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UNRESTRICTED

## **Carol Komaromy**

M.A. Sociology Research in Healthcare, University of  
Warwick

B.A. Open (Hons) Class 1, Open University

# **The production of death and dying in care homes for older people: an ethnographic account**

PhD

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## ABSTRACT

This thesis explores 'death and dying' in care homes for older people. Residents who are admitted to care home institutions are increasingly more likely to be extremely old and frail and it follows that the final product of most care homes is death. Indeed, up to one third of care home residents will die each year.

In particular, the thesis explores the gap between the rhetoric of a 'good death' that heads of homes were keen to produce and the practice reality of what happened when a resident was categorised as 'dying' and at the time of death. The study draws on ethnographic data from one year of participant observation in eight care homes in England. Observing the daily life events in care homes for older people has illuminated the strategies that staff and residents deployed to manage 'death and dying' and the complexities of managing the narrow margin between life and death.

The materiality of the body is not something that can be controlled or contained easily within a category. The findings highlight performances around death and what purpose these might serve, including the role of symbolism in the production of 'living' and 'dying'. They also show how the ageing body might resist powerful practices. The thesis draws on the literature of symbolic interactionism, the sociology of the body and anthropology to explain how the ageing bodies of residents were managed on their journey to death.

The thesis concludes with suggestions on how this type of in-depth study might contribute to practice in those settings which house ageing and deteriorating bodies and which have been marginalised by society.

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# **CHAPTER 1**

## **Introduction to death and dying in care homes for older people**

### **1.1 Why study death and dying?**

This thesis explores what happens in care homes for older people when residents are dying and around the time of death. It is an ethnographic study which probes beneath the surface of end-of-life care to better illustrate and explain the detailed contexts of what it means to be 'dying', how staff decide that this is happening and how they respond to that situation. It is the case that, as those residents admitted to care home institutions are increasingly more likely to be extremely old and frail, the most probable outcome for them is death in the home setting. It follows that, from an institutional point of view, the final outcome of all care homes is death. I wanted to know how staff and residents coped with this in practice since, given the profile of the home residents, it would be much more difficult to provide a distance between life and death. For example, residents in old and extreme old age are close to the boundary between life and death and this boundary is often blurred and less clearly defined than in other dying trajectories. Observing the daily life events in care homes for older people has illuminated some of the strategies that staff and residents deployed and I present these in this thesis.

Given my enquiry into the potential gap between rhetoric and practice it is not surprising that the focus of this thesis is on the staff of these homes. Furthermore, it is also the case that the care home staff were the people with the most power to set and

maintain the rules and rituals that structured what happened around the time of death. It also follows that I explore what this type of detailed account and analysis might offer to practice in care home settings and I do so in the final thesis chapter.

In this introduction I set the scene for this enquiry, explain my reasons for doing the thesis and list the aims which form its focus and from which I developed those questions that I set out to answer. My motivation for doing this thesis is also explained by my own background and I highlight the way that this exploration was underpinned by personal and professional experience. In Section 1.2, I describe an event that I witnessed in one of the homes and discuss the relationship between its starkness and its contribution to the interpretation of my data. The example offers the reader an insight into the difficulties associated with categorising residents as either 'living' or 'dying' which is a central feature of this thesis and serves as a contextualising device for the rest of the thesis. In Section 1.3, I describe the origins of the thesis and its uniqueness as an ethnographic study within a wider national research project. Finally, I describe the structure of the thesis and provide a brief overview of each chapter.

Death and dying is a regular event in care homes for older people. Occurring at the end of a long life, death in old age could be considered to be more 'normal' and, therefore, acceptable than deaths that occur in younger people. In the literature review I discuss the way that in Western culture youth is privileged over old age (Tulle-Winton, 2000; Timmermans, 1998). I argue that there are problems with the assumptions that underpin generalised claims about the social value of life. However, I wanted to explore the extent to which social attitudes to death might infiltrate the institutions of care homes in which deaths in old age and extreme old age took place. Therefore, in care homes for older people, it might be reasonable to expect that there would be an acceptance of death that reflected the wider social view. However, this did not seem to be the case and the extent to which death was not treated as 'normal', but rather as something separate

from life and something that seemed to require special management, offered an interesting contradiction that is part of what I explore in this thesis.

My own background and interest were part of the motivating features for this thesis. In Section 1.3, I describe how the commissioned study within which this research took place, afforded me the privilege of being able to collect and analyse data for this thesis and thus shape the investigation and analysis that was going to be 'my own.' Here, I discuss my personal motivations and explain that I have been asking questions about the 'special' nature of death in institutions for over forty years. I will discuss this further as part of my discussion of reflexivity in Chapter 3, which considers methodology.

In my professional background in health care, I have been involved in death and dying in many different settings. I am also a trained counsellor in the area of loss, therefore, I felt equipped to be able to handle sensitively any distress that people might express as well as coping with my own feelings. Personal experiences associated with death and dying also played a part. When I was 12-years old my grandmother suffered a stroke and died at home a month later. My gran had 10 children, four sons and six daughters, and four of her daughters took it in turns to nurse her at home. She was terrified of hospitals and at regular intervals extracted a promise from her daughter Louie, with whom she lived, that she would not be 'sent' there to die. This was agreed so that when my gran suffered a stroke Louie set up a rota for her sisters as 'volunteers' to cover either a night or a day of being with her. My mother did not want to take her turn to do her night vigil and so I went with her to provide some support. Waiting for gran to die, but wanting her to live, stirred a mixture of emotions inside me. Partly, I was curious to witness the moment of death and see what happened, and also, I was terrified and did not want to be there. Gran did not die that night, but three days later. She was alone at the moment of death and Louie was upset that she had missed her 'departure'. My mother was relieved that she did not have to take her turn to sit with her mother that night.

The account of these women caring for their mother is poignant in many ways. It tells of the difficulty that is involved in carrying out someone's wishes for the place of death, even when there were several daughters to share the burden and the gendered nature of this burden of care. It also illustrates a common fear that my mother conveyed to me about her two personal taboos – of death and the dark. When I became a nurse, I met the combination of these two taboos often as I witnessed many deaths in hospitals. 'Having a death at night' was something most of my colleagues dreaded. This was the time when wards were reputed to be visited by the ghosts of deceased patients. In my experience, when performing last offices on a deceased patient at night, no-one wanted to be the nurse who stayed with the body while the other fetched a forgotten item for the procedure. Echoing my mother's fear, I hated working the night shift in the semi-darkness and was in a persistent state of fear and, as soon as daylight came, I felt euphoric at having endured another night. It seems, on reflection, that there was always the possibility that I might not.

What this highlights for me that relates directly to this thesis is that, despite the tendency for the medicalisation of death and scientific rationality to dominate hospital routines and practices and what Foucault (1976) has called a 'régime of truth', taboos and rituals exist and run alongside these more rational discourses.

As I was concluding my writing on this thesis, I attended the funeral of my stepmother-in-law who died aged 101 years. The funeral took place in a busy area of North London, which made it impossible to park near to the Church and, therefore, extremely awkward for the hearse to offload Laura's coffin. I felt the ambiguity of 'offloading' her coffin quickly, while parked on a double yellow line, and the need to carry the coffin into the church slowly, as part of a dignified entrance, difficult to resolve. My father-in-law had just celebrated his 90<sup>th</sup> birthday and looked very old and frail. I was reminded of a conversation with a funeral director during my fieldwork, who told me that he felt most upset by the deaths of older people when the partner was left alone and

appeared to be the only person for whom the death was significant. The funeral was complicated further by the fact that my partner's cousin, Denis, had died suddenly at the age of 60, just a few days prior to the funeral, and this was the focus of the conversations in my partner's family. Laura's death was positioned as less significant than that of Denis because of the timeliness of her death near the end of her life and the untimeliness of his. Indeed, the last twelve months of Laura's life had been spent in a residential care home and she had faded from the social scene, no longer able to attend any social events, including her husband's 90<sup>th</sup> birthday party. Denis had died suddenly during a bell ringing session at his local church.

As I sat on a pew wondering about my own lack of emotion, I began to watch the event, as if from a researcher's point of view. The funeral is worthy of much more comment but most significantly, it reminded me that the subject of the research that I had chosen to undertake and which had dominated my thoughts for several years, was present in my everyday life. Furthermore, that despite all attempts to separate out death and dying, that I had been observing in care homes, at some level these boundaries are inevitably breached. Using age as a way of keeping death in its place is a device that we use as individuals to keep death at a distance and ourselves safe. Despite this, it seemed to me that, just as the categories of 'living' and 'dying' which the care home staff impose and which I discuss later, were constantly unravelling, so too, the boundary between private and public and personal and professional, cannot be secured.

I have disclosed my motivations for the thesis alongside what it is about in order to set the scene. In the next section I further contextualise this by describing a scene from my observational data in one of the care homes. The everyday life in care homes for older people does not easily lend itself to analysis, categorisation and theoretical interpretation. Just as the life/death boundary is slippery and difficult to define in this setting, the data that I collected for this study have presented their own analytical challenges. The following account helps to illustrate the harshness of institutional living

and serves as a reminder of how this is experienced by care home residents and the way that the calm of routines can be shattered by an extraordinary event.

## 1.2      **Disrupting the calm: painful bodies**

The materiality of ageing and dying residents’ bodies is not something that can be controlled or easily contained within a category. Indeed, just as the body is in a state of decline, so too the categories of ‘living’ and ‘dying’ that the staff used to try to contain them are likewise always unravelling.

One afternoon during my fieldwork, I was sitting in the dayroom of a care home in the West Midlands called Regis Home and talking to Mildred, a resident with Parkinsons’ disease, about her illness. Mildred told me that her dependency caused her much distress and that, for her, this was the worst aspect of the illness. Our conversation was interrupted by what follows (All the names of people and homes have been changed):

**Account from fieldnotes**

While Mildred talked to me, two care assistants (who had just finished their tea break) walked into the dayroom pushing Alice in a wheelchair. Alice had been resting in bed. She was very pale and seemed to be withdrawn that afternoon – this was out of character for her and I felt concerned. June and Lucy lifted Alice out of the chair (each put an arm under her shoulder to lift her) and Alice groaned loudly, *Ooooooh*.

*What is it?* Lucy asked.

*My leg!* Alice was clearly in distress, but Lucy and Joan continued to swing Alice round and drop her into her chair. This movement was not gentle and Alice was plonked, rather than eased into the chair. The chair tipped back slightly and hit the wall! Alice screamed. This time everyone

in the dayroom stopped and looked at Alice. I felt a dreadful sinking sensation because of her obvious pain and distress.

*All right* said, Lucy. She touched Alice's hand. Alice kept her head down but was rocking in pain and frowning with her eyes closed. She did not respond to Lucy. June and Lucy turned and wheeled the chair out of the dayroom.

I could not believe their apparent lack of concern. I rushed over to Alice and tried to comfort her. I put my arm around her shoulders. She was crying now. I felt inadequate but I wanted to help. Alice's friend Martha was sitting in the next chair – she looked very concerned and reached for Alice's hand and held it in both of hers. Alice cried more openly, her sobs shook her body.

*It's all right, love*, said Martha, *It's all right*. This was not the same *all right* that Lucy delivered as a firm reassurance. Martha's *all right* seemed to say, *I am here with you*.

I was very upset. I felt a mixture of anger and compassion for Alice and went to seek out matron and talk to her about the need to improve Alice's pain control.

Later in my hotel after I had eaten a meal I reflected on what the event with Alice meant to me as a researcher.

### Recorded reflections on my fieldnotes

*To what extent is it legitimate to be someone who intervenes in this type of event and how does this affect my data? Will this reaction affect the way that I privilege this type of data over other 'less dramatic' forms? Do I give equal weight to acts of kindness? I have grown very fond of Alice in the few weeks that I have known her. She has told me a lot about her life and has been open and generous in the detail of what it meant to be living in the home. This throws into contrast, the less acute, chronic misery that I have seen in people's day-to-day lives and the loss of dignity that seems to be part of the 'routine' of communal living.*

*All that I can continue to do is to challenge my fieldwork through this type of reflection. Not that I consider it is possible to be 'objective' but to ensure that what I am doing is trying to be as open as possible about what is taking place here.*

I use the extract here to highlight the way that, when I applied theory to my data, I imposed an artificial order on something that was much more complex and difficult to analyse. The categories I used in the thesis to explain what was taking place in care homes were a necessary part of analysing the data but the categories did not capture the 'messy' terrain of the experience of 'dying' in a care home. However, I wish to make an important distinction here. I did not impose an order on the arbitrariness of 'living and dying' in care homes, rather I ordered an explanation of the strategies that people involved used to manage the sometimes intractable difficulties associated with being in this environment. They suffered similar constraints, but here, I am not only claiming that reality is both complex and multi-layered, I am also seeking to elucidate something of what might be lost in any analysis. These are the implicit categories within which staff sought to manage the unravelling of identities and bodies at the end of life. Furthermore,



part of what was happening also involved my part in this thesis and the motivations behind my interest as I described in the introduction.

In the data chapters of this thesis, I have told the story of Alice's dying and her death. As a description of the everyday life which underpinned the analysis, it is important also to show the suffering in its raw and mundane sense not only to offer a context, but also, to show that underneath the explanations that this thesis produces there are lives being lived out in institutions such as Regis Home that involve degrees of suffering and loss of dignity, as well as expressions of love and care from the care staff and between residents. My field note example demonstrates what it is that both residents and staff had to deal with and how they did so is the story of this thesis.

### **1.3 The origins of the thesis**

In essence, this is an ethnographic study within a large multi-method commissioned project (Sidell *et al.*, 1997) which investigated the case for palliative care in care homes for older people. I discuss the methodology for this thesis in Chapter 3 but here I outline the relationship between the thesis and the commissioned study. In 1994 I joined the Open University as a research fellow on a multi-method investigation into the need for palliative care in nursing and residential homes in England. The study was conducted over a period of two and a half years. The first six months of Stage 1 comprised a postal survey questionnaire and, for the next two years, I was in the field, first, interviewing heads of homes for Stage 2, and second, for Stage 3, as a participant observer in eight homes. It was while I was conducting and analysing the Stage 2 interviews that I began to formulate questions that arose from the tensions and contradictions that I perceived in what people were telling me about death and dying. I conducted the interviews with 84 heads of homes in three regions of England and was often provided with a tour of the home after the interview, so that I was able to see a snapshot of residential life in these settings. However, it was not just what heads of home told me at interview that

stimulated my interest in the subject of this thesis, waiting to enter the home and seeing these settings as an outsider, positioned me as a stranger and provided me with many insights into life in these homes. For example, I was struck by the way that residents were either moving around or being moved around the home. I noted that mealtimes seemed to dominate all of the home routines. This affected the time when it was convenient for heads of home to talk to me and, also, the time when all residents seemed to be brought into the communal areas. I recorded the data associated with these first impressions carefully and, together with the interview data, raised the key questions that form the basis of this thesis that went beyond the investigation into the need for palliative care. The time I had for reflection and refinement during Stage 2 of the commissioned study (Sidell *et al.*, 1997) proved to be extremely advantageous and meant that I had a clear focus for my observations when I entered the homes. This was important at the stage at which I negotiated access because I needed to be clear about what I was negotiating.

Table 1.1 below summarises the commissioned study that took place between November 1994 and July 1997.

**Table 1.1 Stages of commissioned research**

<b>Stage 1</b>	A postal survey of 1 000 homes in three geographical areas in England.
<b>Stage 2</b>	Tape-recorded interviews with 100 heads of homes, sample from stage 1.
<b>Stage 3</b>	Participant observation in 12 homes selected from stage 2.

(Komaromy, 2002)

As stated earlier, many of the issues surrounding the topic of death and dying raised at interviews with heads of homes in the commissioned study (Sidell *et al.*, 1997) seemed to

be contradictory and internally inconsistent and in this thesis I explore the gap between what the heads of home told me and what actually happened during death and dying. I also analyse the strategies that care staff and residents used to manage this gap between rhetoric and practice.

Furthermore, during interviews with heads of care homes, I noted from what they told me that, while death was a regular event, it was not treated as routine. This was one of the inherent contradictions at the heart of this thesis. If death is the natural outcome of a long life, why was it talked about by the heads of homes at the Stage 2 interviews as being a special event? This is not to suggest that during the interviews, death was always interpreted as a negative event to be feared and postponed, but rather, that it seemed to require both special treatment and an explanation and, as such, was positioned as 'out of the ordinary'.

There are several reasons for the apparent contradiction that explain why death might be more 'special' than 'normal'. First, I was enquiring about death and dying in the home and I was the person who set up this topic as significant. It seems reasonable therefore, to assume that heads of homes were responding to my focused questions. However, my own interest was reflected in the willingness with which those heads of home that I interviewed talked about death and dying. In other words, the people that I interviewed about death and dying told me, both at the point of setting up the interview appointment and at interview, that it was a 'special' event and that they welcomed the opportunity to be able to talk about this 'neglected' topic.

Second, it is entirely feasible that events can be both routine and special. For example, based on my professional experience as a midwife, in maternity units, births are constructed as special events, but they are also the routine business of these units. All of the work that takes place in maternity units is focused on the birth event, and routines exist for all eventualities. At the same time, the event of birth is also celebrated as being special and unique to each mother and partner. Therefore, it is possible to keep events

such as birth distinct, and yet, have routines and protocols in place that guide the actions of the staff of the care setting. I was left with the question about why did this not happen in care homes for older people where most residents would die. To continue this comparison with birth, does the unpredictability of death (as opposed to birth with its clearer period of gestation) explain this apparent lack of focus on death? Third, since, there is a legal requirement that each individual death in society must be explained and recorded, this requirement frames the way that death is positioned as a significant event for which the state requires a formal explanation. However, I wanted to evaluate the extent to which this formal requirement might influence the position of death in care homes.

Despite the above qualifications, I remained puzzled about why it was that in a setting where you might expect people to be more used to death and dying, there did not seem to be an acknowledgement that death was a routine event. It became clear to me that there was a tension here and I wanted to be able to explore this during my fieldwork in selected homes.

## **1.4 The aims of the thesis**

I have described the way that questions arose from the tensions that emerged from interviews with heads of homes about death and dying. I had anticipated that there would be a gap between the rhetoric from what I heard at interview with heads of homes in the commissioned study and what I observed from being present in the homes during my fieldwork and this was the case. The initial shape of the thesis evolved in a gradual and piecemeal fashion during the field work in eight homes over the period of one year. My findings were influenced by the impact of the distillation of present data upon future data collection and I return to this in Chapter 3. Here I want to highlight that it was important to keep the research agenda open for as long as possible, and therefore, in

essence, the aims do not represent the dynamic and more contingent aspects of the process of refining the focus for this thesis.

At the start of this chapter I stated that this thesis explores why death might be constructed as 'special' in settings where it is an anticipated event. For example, at interview for Stage 2 of the commissioned study, heads of homes explained to me that it was important for the home to be able to provide a home for life and that the resident should be able to die in his or her 'home' if this is what was wanted. They also expressed the view that death at the end of a long life was a '*natural event*' for which residents were '*ready*'. However, heads of homes also talked to me about how they needed to protect the surviving residents from the sight of death since this was likely to be upsetting to them. In the list that follows, I have summarised the key points from these Stage 2 interviews and italicised those words that were commonly used by heads of homes. Therefore I wanted to explore:

- What wanting residents *to die in the care home as their home* meant for older people?
- What was meant by the phrase *death is a natural event for residents at the end of a long life*; in particular, what happened at the time of death that produced it as a 'natural' event?
- In what ways might residents be *ready for death* and how was this understood by residents and home staff?
- Why did residents *need to be protected from death* (as the heads of many homes suggested at interview through such phrases as the need *to keep it from them* and *not stuffing it under their noses*) and how was this carried out?
- What did it mean to be 'dying'? How this was defined and how was this different from 'living'?

## 1.5 The structure of the thesis

In the next chapter, I discuss the literature that I used for this thesis in detail. I provide a rationale for the position of this thesis within its theoretical paradigm and in Chapter 3, I explain how this suits the methodology. Essentially, because this was an ethnographic exploration of what happened to older people who were dying in care homes and the extent to which the production of death was also a performance, I used an interactionist interpretation. In particular, I used Goffman's (1959) dramaturgical approach in symbolic interactionism to explain the 'reality-constructing' behaviour of care home staff. I also drew upon the rites of passage literature to consider the boundaries that were constantly negotiated by the care staff and residents (Douglas, 1984; Glaser and Strauss, 1965a). Literature on the sociology of the body helped me to explain how the bodies of ageing residents were managed in the way that they were and for this I drew upon literature from Turner (1987, 1992), Featherstone and Hepworth (1991), Tulle-Winton (2000) and Foucault (1976 and 1977).

Following on from the literature review, the first part of Chapter 3 examines the methodology and I discuss the appropriateness of an ethnographic account to this type of enquiry; while in the second part I discuss the methods that I used to collect the data. Chapters 4–7 provide the empirical analysis of my observations and are ordered to reflect the trajectory of dying in care homes. In Chapter 4, I consider what it means to be 'living' in care homes for older people and how this status is produced, while Chapter 5 explains the production of 'dying' and the privileges that this status afforded the residents in care homes. In Chapters 6 and 7, I focus on the event of death. The discussion in Chapter 6 of the ways in which anticipated death was managed uses two accounts of the death of residents, one of which is the death of Alice, whom I introduced in this introductory chapter, and the other is James, who was a resident in a local authority-owned care home. By contrast, Chapter 7 considers what happens when death is not anticipated and

is sudden. This data chapter provides the basis for a discussion of many of the key questions of this thesis.

In my conclusion, I consider what this all means for those who live, die, and work in care homes for older people. I also reflect on the nature of the wider relationships that are involved in such a study. Having considered how dying is produced, I reflect briefly on how this thesis has been produced and acknowledge the relationships that have helped me to shape, understand and complete this thesis. I end with a consideration of the significance of the conclusions of this thesis for practice.

## **CHAPTER 2**

### **Literature review**

#### **2.1 Introduction**

In this chapter I discuss the literature that relates to death and dying in older people. This review serves several functions. It informs the reader about what the existing academic literature has to say about the subject; what type of enquiries have taken place already and my own position within that terrain. It also informs the reader of the disciplinary approach that I have taken. As a sociologist making a sociological enquiry into care home institutions, I was interested in presenting a sociological version of reality. My examination of ageing bodies in time and space was well suited to Goffman's (1959 and 1961) symbolic interactionist explanation of body management, although there are limitations to this approach as I discuss later. Understanding an institutional world that is both part of and separate from society involved me in examining the boundaries between the private and the public, as well as the boundaries between 'living' and 'dying' and life and death. Shilling (1993) claims that sociology of the body theorists have taken great interest in the anthropological view of the body and that this highlights the extent to which disciplinary boundaries have also shifted in post modernity. The work of the anthropologist Mary Douglas (1984) helped to explain what was happening at these boundaries as well as the social status of the body near to and at the time of death. I also needed to understand and interpret the significance of 'living' and 'dying' trajectories of care home residents and for this I drew upon the sociological theories of Glaser and



Strauss (1965a) whose work on illness trajectories and the corresponding social significance within health care institutions is seminal.

Because the focus of the thesis is small groups of older people living together in care homes in England, I will limit the discussion to death and dying in Western societies. The chapter begins with a broader consideration of the profile of death in England which sets the scene for the literature on attitudes to death and dying in these societies, which follows. The focus then narrows down to a consideration of the way that death and dying is managed and, in particular, the deaths of those ageing and frail bodies of older people. Here I draw on literature around the sociology of the body (Douglas, 1984; Tulle-Winton, 2000; Hallam *et al.*, 1999; Lawton, 2000). I focus not just on the way that older bodies are viewed and treated but also on the inherent dangers in 'dirty' leaking bodies and bodies which may be seen as containers of death. To some extent, this literature highlights the way that ageing and decaying bodies nearing death are both socially and theoretically marginalised. These theories of 'bodies' do more than offer an abstract explanation; they also highlight aspects of the empirical 'reality' for older people who are dying.

## **2.2 Death and society**

The number of people who die, the reason that is given for their deaths and their age at death, are all factors that feed into the way that death is constructed by any society. The fact that in contemporary Western society we record and count this information is itself pertinent as I will show. How society responds to death and dying is, therefore, in part, a reflection of changes in demographic patterns of death. For example, decreases in deaths from infectious diseases that were associated with poor sanitation and living conditions up to the second half of the twentieth century and the reduced infant mortality rate have made the threat of death less of a proximal reality for people living in contemporary

Western society. In this section I discuss the state of death in the UK from statistical evidence and move on to consider deaths in institutions.

## **2.3 Death in the UK**

Over half a million deaths (557 789) take place in England and Wales each year (ONS, 2002). In the United Kingdom over the past century there have been dramatic demographic changes that are reflected in age-specific death rates for example, at the beginning of the 20<sup>th</sup> century 24 per cent of deaths occurred in people over the age of 65 compared with 83 per cent by the end of the century (ONS, 1999).

### **2.3.1 Institutional death**

In 1998 institutional deaths accounted for over 400 000 per year of the total deaths across all ages in England and Wales and, of these, over 300 000 took place in NHS hospitals (OHS, 2000). Deaths in people over 65 accounted for nearly 250 000 of all deaths in hospital. Twenty-three per cent of deaths took place in care homes, the majority of whom were women over 85 (ONS, 2000). The number of people who die in their own home each year is proportionately low, for example, typically twice as many people died in 1998 in psychiatric hospitals as at home (2000). As well as age, therefore, place of death needs to be taken into account in exploring the way that death and dying is experienced and managed. For example, the way in which death and dying is situated in institutional spaces might suggest that there are reasons to conceal or in some way to contain the event.

The 1990 NHS and Community Care Act (Department of Health, 1990), which was implemented in 1993, had a dramatic impact on the care of dying older people. One of the effects of the Act was the decrease in NHS long-stay care. Statistics show that between 1970 and 1998 the number of long-stay NHS beds fell by 54 percent (ONS, 2002). With the burden of care previously absorbed by the NHS, now relocated to the

community, difficult decisions had to be made in the face of finite resources. One of the consequences of the increase in need for care of older people in the community was that the available money was targeted at a small group of people considered to be most in need of care. For example, the intensity of home help increased while the numbers of households in receipt of this help decreased (Department of Health, 1999). In other words local authorities provided more intensive services to a smaller number of service users. Added to this is the reality that twice as much money was spent on residential care as on non-residential care for older people (Department of Health, 2000). Furthermore, Peace (2003) argues that the post-Thatcher financial changes since 1979 were fundamental to the increase in private sector provision of care home placements. One of the consequences has been that the profile of older people in care homes has changed to one of greater needs. According to a study by Bajekal (2002) in English care homes three in four of all residents were severely disabled. While the main contributing factor to this disability was dementia, and while most were in dual-registered or nursing homes, the physical incapacity of residents contributed significantly to their state of wellbeing. There is more likelihood that residents will suffer from chronic conditions associated with ageing, who will be further along the illness trajectory to dying and death.

Mozley *et al.* (2004) make the point that reliable data on the causes of death is difficult to acquire, both because it is incomplete and information on residents in care homes for older people is not available separately. Having made these qualifications their study findings from physical health comparisons between 300 residents showed a death rate of 30 per cent in a nine month period. This echoed the findings of Bebbington *et al.* (1996). The study also showed that the residential and nursing home residents who died soonest were those who had the highest measured dependency on admission. Taken together these aspects of care mean that in care home settings death is an increasingly regular occurrence (Sidell *et al.*, 1997).

The management of death and dying in society is therefore influenced by a number of factors. Many of these factors are in a dynamic relationship with each other. Furthermore, the place of death and the profile of those people who die influences attitudes and responses to death and contributes to the way that death is defined.

Other factors that influence the way that death is viewed and managed in society are those wider attitudes to death in contemporary western culture and this is the focus of the next section.

## **2.4 Attitudes to death in contemporary Western culture**

Meanings associated with death have changed over time along with the way that society manages death and dying. Like birth, death has become medically constructed and the medical interpretation of death and dying is founded on a biological base (Stacey, 1991). The biologically determined and 'medicalised' body thus demands a medical response (Levinson, 1998). However, as I have previously argued in Section 2.3.1, it is less likely that within finite health resources, priority of medical care will be given to the growing numbers of older people. Therefore, while claims about the professionalisation and medicalisation of death might be supportable in terms of its dominance in western societies, making a universal claim about the way that society views death is contested; not least by the way that death and dying in older people is managed. It follows that while the event of death is one that has to be legally and medically defined, the postponement of death that medical technology offers is usually reserved for younger people. For example, there is evidence to suggest that the amount of heroic intervention that is undertaken to save life is age-specific and focused on younger people.

The classic study by Sudnow (1967) on the strong relationship between the strength of the attempts made to resuscitate patients who came into the emergency department of a US hospital, and their age, background and what he called their moral character supports the argument that deaths in older people are less likely to be

postponed than those of younger and morally 'worthier' people. If a death becomes the result of the failure of rescue medicine, then older people are less likely to experience a medicalised death than younger people, since there seems to be a direct correlation between the way that people are valued in society and the extent to which rescue medicine is applied.

Given that medical technology is an increasingly dominant force in postponing death, forty years later Timmermans (1991) revisited the work of Sudnow (1967) and, from his findings argued that, in terms of 'rescue medicine' at least, the younger a person is, the 'worthier' they become of being saved. But more than this, in his study of resuscitation he found that age and social worth were markers that resulted in the tendency by emergency staff to marginalise older people. He noted that, while legally compelled to attempt to resuscitate everyone in the emergency department, staff made limited and futile attempts to do so with older people. Like Sudnow, Timmermans (1998) found that social rationing and discrimination according to age continued to take place.

Likewise, the status of professions within medicine parallels this, so that, in an evaluative hierarchy such as medicine and nursing, those who work in neonatology hold a much higher status than those who work in geriatric care (Komaromy, 2001). According to Featherstone and Hepworth (1991), the 'youth' culture of the late modern/post modern era is in the ascendancy. Certainly it is the case that this group features most centrally and frequently in the media. Featherstone and Hepworth also claim that youth is largely positively imaged, while negative stereotypes are more commonly associated with ageing. This form of ageism is documented in other ways. Henwood and Harding (2002) argue that, at a time of rising medical costs in the UK and with the twin explanations of this rise in terms of costs of technology and demography, older people are positioned within explanatory discourses as being 'too costly'. While the way that older people are positioned in the discourse of resource allocation affects attitudes to their entitlement to care, Bytheway (1995) points out that ageism presents itself as a set of norms and

practices that take place around people who are defined as 'old'. This suggests a more direct impact on the experience of care for older people.

Therefore, while death is an event for which there is always a legal requirement for a medical cause to be provided, within the medicalisation of death thesis, there are age-specific divisions. I have already made the point that death treatment is age-specific and that older people are positioned at the lower end of resource allocation. The status and privilege of particular forms of medicine combined with a 'youth culture' suggest that death and dying have been subject to changes over time and it is this aspect which I turn to next.

### **2.4.1 Historical constructions of death and dying**

According to Ariès' (1981) historical and cultural analysis of death, during the eighth to the nineteenth centuries death was acknowledged as part of life. After this period, he argues, death became more hidden. He further argues that the place, medical regulation and professionalisation of death have all served to redefine death as being no longer a private affair (Ariès, 1981).

What he means by this is that death has become the business of the legal and medical profession. But this is only one aspect of the 'non-private affair' of death. Ariès argues further that there was a time in western culture when death was viewed as a 'natural' event. He claims that changes in attitudes to death affected not only the people close to the deceased person, but also the wider community. The paradox is that while death was more privately 'owned', it was an event that belonged to the local community in the sense that through practices at the time of death and immediately afterwards, the local community mourned people who died. For example, it was customary to visit the deceased person and declarations of a death were posted on the front door of the deceased person, whose house was left open to encourage such visits. As Ariès claims, it

was not just the family who were bereaved but also society and, as such, death was a social and public event.

Death was certainly a more regular event during the periods to which he refers and the reduction in the death rate in western societies partly explains the lack of familiarity with death. But for Ariès (1981) more than this has taken place. He argues that a change that he calls the 'beginning of the lie' (p. 561) took place after the nineteenth century, in which death in Western society became concealed. He does not argue that attitudes over the 14 centuries were static, rather that attitudes to death prior to World War I changed incrementally over time so that in the thousand years preceding World War I it is difficult to note specific changes. By contrast, in the post World War I period the rate of industrialisation, urbanisation and technological change, especially the advent of television all combined to accelerate the change in attitudes to death and, therefore, made them *markedly* noticeable. Ariès also claims that one of these changes was that death became a taboo subject and was no longer a 'natural' part of everyday life. For example, the harbinger of death was traditionally the priest; this is no longer the case and even the last rites have been replaced by the sacrament of the sick, which is disassociated from dying and death. According to Ariès disclosure of the imminence of their death to the dying person has been postponed and replaced by what he calls 'dissimulation'. The consequence of this is that even dying people are shielded from the knowledge of the imminence of their own death. It would seem that Ariès is arguing for different rates of change, with a dramatic acceleration period where different elements provide sufficient momentum to produce a paradigm shift in attitude. Death once 'natural' became a taboo subject and Ariès cites World War 1 as the marker of this shift.

Ariès is a French historian who carried out extensive research into attitudes towards death in western Christian cultures over the last 1000 years. Ariès' (1981) claims are based on two assumptions, both of which are problematic. First, historical comparisons assume the possibility of being able to present a coherent and universal

account of social behaviour. Even recognising that all social events are within a cultural and historical context, it is not possible to represent a unified, conceptual view of death. Second, there are difficulties in being able to capture culture in society as if it is monolithic and fixed. So that while current debates about the nature of society position culture more prominently, and as something through which all experience is mediated (Hall, 1992) and shaped, it is important to recognise that social events are culture-bound and culture is not fixed but rather fluid, multifaceted and diverse.

In contrast to Ariès, Elias (1985) challenges the idea that death in the past was 'natural' claiming instead that it was painful, because life was much shorter and more dangerous. He argues that rituals and routines associated with death, which were under the control of individuals who were privately connected to the deceased, have been taken over by professionals. Therefore he agrees that, while there have always been routines associated with death, the distinction currently is that they are institutionalised routines. More significantly, for Elias the difference is that current cultural norms and codes of behaviour are performed by people who lack the same emotions as those who are intimately connected with the dead person. The result, argues Elias, is that dying people are more isolated than in the past.

#### **2.4.2 Medicalisation of death**

The medicalisation of death and dying is relevant to this thesis in two main ways. First, it suggests that there is a need to explore the extent to which the dominance of medical knowledge and medical interpretation of death influences the management of the death of older people in care homes. Second, the position of older people in society, as less likely to receive high levels of medical intervention than younger people, could be linked with a view of their deaths as being unavoidable and even desirable in their timeliness. For example, this might suggest that death in old age and extreme old age might be non-medicalised *by default*. There is a legal requirement to register every death and in doing



so to classify its cause, but how far does the dominant scientific, rational paradigm demand an explanation for this type of death?

Gorer (1965) captures the ambivalent nature of death in the twentieth century by contrasting the loss of death as a 'natural' event with the large volume of violent death that is presented in the media. For Gorer there is a different type of death being publicly portrayed and, rather than death being a taboo subject, it is 'natural' death that has become concealed and taboo.

Arguing from the position that medical knowledge is a dominant discourse in contemporary Western society, Armstrong (1987) challenges the notion of the 'silence' around death. He claims instead that in a society in which individualism dominates, and where death has become medicalised, there is not a silence about death, but rather, a different way of talking about it. In other words, the discourse of death has changed from a 'natural' to a 'medicalised' one. The formal practices around death such as notification, medical certification and the way that professionals handle the dead body have all served to make death a special event. Furthermore, the need for information in order to be able to certify death is a legal requirement and one which places a great demand on professional carers being present at the moment of death. Rossenbatt *et al.* (1976) argues that the medicalisation of death is itself a form of ritual that involves medical people as the specialists who witness death. Both the medical construction of death and its legalisation requires there to be a precise time given to the moment of death, even though there are ambiguities to this diagnosis (Turner, 1987). These practices support the notion that death is not 'natural' and that it needs to be scrutinised and managed. This is an important and relevant argument because it suggests that death remains a significant event in society, but its constructions and status change over time. This has implications for the ways in which death and dying is managed in care homes for older people.

Part of the exploration of this literature is to consider the implications of this broad medicalisation thesis for what it is that happens around the time when a care home resident is thought to be dying. There are two further key aspects of these arguments that relate to this thesis. Given the 'state' of death in western societies, all deaths have become significant events that need to be *managed* and *explained*. The requirement to register death includes the need to note the cause of death and is based on the assumption that it is always possible to know the cause and that this will be in the form of a medical explanation. If there is doubt over the cause of death, then there is a legal requirement that a post mortem be carried out. This form of scientific knowledge continues to dominate the way that death and dying is constructed. Therefore the public explanation of death will include a medical definition of its cause and also the end period of someone's life, which is more likely to be defined as a 'terminal' illness. This is part of the framing of death in society. Capturing the social meaning of death is difficult not least because it requires that we disentangle attitudes to death from those of grief and mourning, although the nature of death clearly impacts upon the form of mourning, for example the manner of death and whether or not it was anticipated (Hockey, 2001; Ayres, 2001).

Therefore, part of the thesis explores the ways in which death in old and extreme old age is explained in residential care settings. Furthermore the thesis explores the *need* to explain death. It is at the interface between the individual and society that the meaning of events is constructed (Goffman, 1962). The way in which society views the death of older people will make a significant contribution to its meaning in this context. In other words the wider social context of death and dying is in an intimate relationship with the local context. This relationship is not one-way, however, since attitudes to death in old age are also formed by the experiences of the event itself. Prior's (1989) view, echoed by Hockey (2001), is that individual grief experiences are reflected in public expressions of grief. Society shapes death and death shapes society and the way that meanings about death are negotiated forms the core of this thesis.

### **2.4.3 Local context of death and dying**

So what about the local context of death and dying in care homes for older people?

Sudnow (1967) used the term 'social death' to describe the way that a lack of significance derives from the lives of people who are no longer considered to be 'socially productive'.

The term social death refers to the lack of social value of people who might still be 'clinically' and 'biologically' alive. I have suggested that older people's deaths are less likely to be medically postponed than those of younger people. Also, the statistics presented earlier suggest that people are more likely to be admitted to homes when they have high dependency needs. To make sense of the implications of this I turn to the body of literature on the concept of social death (Sudnow, 1967; Timmermans, 1998). Goffman (1961) refers to the 'mortification' and 'non-person' (pp. 24–33) treatment as one of the results of institutional life. He proposes that the fracture between the life outside and the institution which result in the loss of social role places the inmates as people in exile from real life and as such socially dead. This suggests that the inmates of institutions are unable to resist the practices of institutions and that the only social role that has currency is that attributed outside of the institution. Goffman's theories on the effects of institutional life have impacted on the way that care homes (and other institutions) construct an anti-institutional approach to life in the 'home' and is discussed further in Section 2.8. Sudnow (1967) uses the concept of social death to argue that patients near the end of the dying trajectory are treated as if they are already dead. Different definitions of social death tend to build on these two key approaches.

Sweeting and Gilhooly (1997) examined the extent to which social death occurred in older people with dementia. While the work operationalised the concept within family care, it was still helpful to this thesis in that the concept can be understood according to what it is that characterises a person and what it is that characterises a life. Also of interest to this thesis, is the way that the definition of 'dying' changed the way in which residents were treated and afforded them access to specialised 'dying' care. Also helpful is

the discussion of social death by Mulkay and Ernst (1991) who present this concept as one that is a sequence of 'declining social involvement' as a preparation for biological death. This broader definition allows for different age-related and place-related experiences of death to be better encompassed. In particular, for older people in institutions, they argue that the residents participate in the need to separate living from dying in an attempt to negotiate social roles as 'living' residents.

#### **2.4.4 Ageing and death – social death**

Being physically alive and yet socially dead raises several questions for any study of death and dying in older people. What is it that makes people socially alive members of society, and how is that membership defined? Are people who live in institutions part of society? Marshall has written about the status passage to death in care homes for older people that throws some light on what might be taking place here (Marshall, 1975). He draws upon Glaser and Strauss (1965a) ideas on status passage control. For example, from data in one of the study homes in his sample, Marshall argues that, 'the trajectories of dying, as defined in the Home, serve to deny the reality that all are dying, for the definition is reserved for the very final stages, and leads to increased geographical isolation of the 'dying' person on the infirmary floor or in St. Peter's Room' (1975, p. 131). Marshall claims that the way that the home structured death and dying constrained the residents in being able to construct their own meanings. He contrasts this with another community home in which the residents were able to develop 'community control' over the dying status passage. What this study highlights is that meanings about death and dying are negotiated between the home and society and within the home between residents and those factors that comprise what can loosely be termed home 'culture'.

So far I have considered the literature that relates to the social construction of death in UK society. I have drawn on this literature to show how the value that is placed on younger people over older people in western societies means that dying older people

are less likely to be subject to life-saving interventions. The profile of residents who enter care has resulted in an older and a more frail population who are more likely to have multiple and complex needs. The focus on the absence of bodily function combined with a loss of social status suggests that the care of older people might be focused on their physicality rather than any other aspect of their 'selves'. In medical discourse the ageing body is a disabled body (Tulle-Winton, 2000). Therefore, even if it is the case that older people are less likely to be considered as 'worthy' of being actively treated through medical interventions, this does not exclude them from being subjected to medical discourses that construct them as biological entities whose bodily functions are letting them down. It follows that if death occurs more frequently in the institutional spaces of care homes, the nature of these institutions will play an important part in its construction which is both universal to western societies and local to institutional environments. In the next section I consider the focus on the residents' bodies as they enter institutional care and how this might affect death and dying.

## **2.5 The problem of old bodies**

In recent years the body has received much attention in sociological and other academic writing. It is particularly relevant to this thesis in that the notion of a plurality of bodies is in tension with the dominant medical discourse, which claims that it has a universal nature, a reflection of the fact that within this discourse there is a need for universal 'truths' about a single body (Turner, 1987). The tension between bodies that are invested with types of social meanings, such as 'performing' (Goffman, 1959), 'passive' (Illitch, 1977) and 'docile' (Foucault, 1977) and single, medicalised bodies that are biological entities is both ideological and epistemological. This tension runs through the thesis. For example, the need for certainty might seem to be unrealistic in terms of being able to predict when death might occur but it is through defining the cause of death that medicine has claimed ownership of the body and confirmed it as a biological entity. Armstrong (1993) argues that medicine requires certainty and that for medical

practitioners to give up this certainty of the 'universal truth' of the body would result in contradictory truths. The rationale for holding onto this positivism and common sense is encapsulated by the following quote. Hughes (2000) argues, 'Medicine (...) cannot survive as an effective practice without assuming that the body that it seeks to mend is a secure and orderly thing that is obedient to the laws of anatomy and physiology' (p. 13).

In medicine, the way that the body is understood affects the practice of medicine and health care. I referred to the supremacy of youth in Section 2.4.2 and with youth positioned as superior with old bodies representing negative stereotypes of human embodiment. Tulle-Winton (2000) argues that, despite gerontological literature's exposure of the dangers of this myth and attempts to redress this with positive images of ageing, the old body remains marginalised and in need of concealment. The current shift in medicine suggests that the medicalised body is no longer passive but in need of individual responsibility for his or her own health and therefore 'active' (Martin, 1994; Giddens, 1991). This seems to further marginalise the passive, old body, which is strongly associated with a lack of strength and degeneration and representing a precursor to death. It also raises the question about how dying in old age might be constructed. For example, is it a 'natural' outcome of decline or is it medically constructed as a terminal illness?

Tulle-Winton (2000) further claims that the creation of old bodies that are signified as decay, loss and obsolescence both creates and legitimates the need to control them. While Hughes (2000) argues that young bodies are active and in need of constant maintenance, Tulle-Winton (2000) claims that old bodies have become problems in need of solutions. Part of this management, she argues, is through a series of strategies that include medical responses to cures of ageing, control, concealment and confinement. Therefore, according to Tulle-Winton, old bodies that cannot be self-regulated become the responsibility of other agencies and governments. It is this focus on strategies of managing older bodies that are approaching death that is the core of this thesis.

Turner (1992) argues that biomedical knowledge of the body does more than explain what is taking place biologically. This idea, based on Foucault's 'clinical gaze' (1976), suggests that this is much more than an application of knowledge but also a form of regulation and control. Drawing on the writings of Foucault he argues that 'power and knowledge' are interchangeable. More than seeing knowledge enshrined within powerful dominant discourses, such as the medical discourse, he argues that knowledge is power. Turner argues, further, that medicine's capacity to cure infectious diseases in the twentieth century increased its position of power. The chronic diseases of the late twentieth and early twenty-first century present a problem for medicine and challenge its position of certainty. Thus, it seems that 'disabled' bodies are constructed as being in need of management because they lack 'normality' and are 'failing', not only biologically but also medically. Tulle-Winton (2000) argues that old age is embodied in ageing bodies that has excluded the social dimensions of age, and this material body not only excludes the social dimension of being old but also produces them as 'other' and not part of social life. She further argues that literature which foregrounds the social and cultural dimensions of the ageing body ignores its biological reality, as if this is made invisible. What is lacking is a fusion of the social/cultural and physical/biological body in old age. Hallam, Hockey and Howarth (1999) discuss ways in which the body is the site at which the individual and society 'mesh'. They also discuss ways that identities of older people who are approaching death are constructed through discourses. They argue that the exclusion from social roles that is associated with ageing, and this positioning of older people as having suffered degrees of social death, fails to take account of their embodied experiences. If older bodies are defined as socially dead, then the journey to physical death will be shaped by this definition. With the body as an object lacking social meaning, the identity of older people is erased. While the authors argue that the old body can constitute a powerful physical resource, this also raises the question about the extent to which older people's bodies resist the powerful resources that define them according to discourses associate with ageing. This literature was particularly helpful in my

consideration of the way that the body of older people became the dominant feature of their identity and also the focus of care. It is mostly through what is happening to the bodies of residents that care 'solutions' are formulated and decisions made about where that care should be provided.

The literature on ageing and medicalised bodies makes the case for the social perception of older people as 'other' and highlights the way that this is constructed as a negative image. However, I would like to add a note of caution to the arguments that highlight the dangers of the medicalisation and problematisation of bodies. I would argue that one of the dangers of a resistance to negative stereotypes associated with ageing and the creation of positive images is that it echoes the countering of one danger of institutionalisation by reframing it as rehabilitation. Both positions, the negativity of ageing and the resistance to this, fail to address the diversity of health statuses within a community of older people. This thesis explores aspects of this reality through constructions of 'living', 'dying' and 'death' and how these states might be ascribed both to the home's community and to its individual members.

## **2.6 Managing death: producing the 'good death'**

Here I consider the literature about good death and the way that this might be interpreted within care home settings for older people. The concept of a good death has historical and cultural significance. However, it is not a straightforward concept. In the interviews for Stage 2 of the commissioned project, heads of homes were asked about their views of what made a 'good death'. The hospice movement has marshalled the concept of a 'good death' as a basic human right for all dying people and for those people who work in health care the term carries particular significance. Neuberger (2004) writes that in order for healthcare workers to enable people to have a good death that they need to understand what individuals want as well as knowing how to provide a 'good death'.



*It should enable us to use the experience to show others there is nothing to fear. What we are doing is shedding this life, in peaceful manner. No mysteries, no horror, no agony. Instead a peaceful end, as we want it, in as conscious a partnership as possible with those who have been our life's companions and friends, supported by professional care provided by people with great skills in pain relief and emotional support.*

*(Neuberger, 2004, p. 16)*

This type of idealised death has received much criticism. Corner and Dunlop (1997) argue that good death has become routinised and more likely to meet the needs of staff and conform to the social expectations of the organisation, than to meet the needs of dying people. The institution would seem to abhor a noisy and dirty death.

For an interpretation of an individualised 'good death' this definition seems very prescriptive. Bradbury (1999) has categorised the concept of a 'good death' into three types which are: the 'medicalised', the 'sacred' and the 'natural', so that it is possible to analyse and evaluate deaths according to each of these types. For example, a 'good' medicalised death might be one that is anticipated and pain-free but this conflicts with the criteria associated with the natural dimension of a 'good death'. To define the concept in this way also ignores the question, good for whom? As early as 1972, Weismann introduced the concept of 'appropriate deaths' that took much more account of the relational aspects of death and the fact that people do not die as isolated individuals but as members of a social group. But however the concept is defined, there is a danger in its suggestion that death can be well-managed and controlled. Bradbury acknowledges the difficulties associated with representations. One way of describing representation is as a way of making the familiar unfamiliar (Moscovici, 1984). Indeed this is part of what I wanted to do in this thesis. However, the key disagreements in academic writing about the dominant state of death, some of which I have rehearsed in earlier sections of this

chapter, highlight the problem of a single representation. This is not necessarily solved by having a series of differently classified representations.

However, the concept of 'good death' is relevant to this thesis and to death in care homes for older people, for at least one significant reason. In homes for older people death is much more likely to be constructed by the home staff, most significantly needs of homes, as a 'natural and timely' event, coming as it does at the end of a long life (Komaromy and Hockey, 2001). The 'good death', as Bradbury argues exists for the sake of those who are 'living' and this is important for the way death is represented to surviving care-home residents. The type of 'good death' that the heads of home talked to me about at interview, was one that was 'natural', 'timely', 'peaceful' and 'accompanied'. This is central to the thesis and is the point at which the difference between the rhetoric of a 'good death' and the practice of terminal care for dying residents is played out according to a script. By this I mean that to produce a 'good death' the heads of homes and the care staff who cared for dying residents needed to be able to translate the concept into practice. The ideology that underpins the 'hospice good death' was borne out of a reaction against the medicalised deaths so often associated with acute hospital care usually when cancer treatment had failed to cure the sufferer.

The idea that deaths can be produced as 'good and timely' death did not seem to arouse staff concerns about the management of death and dying in care homes for older people. There are still problems and concerns associated with death in old age in these settings. The loss of self which older people entering care homes might suffer contributes to the need to give more meaning to life through death-bed rituals (Komaromy and Hockey, 2001). It also creates a potential need for care home staff to manage the end stage of dying so that it does not appear to be discrepant and thus threaten the boundary between life and death.

The care staff in homes for older people have to manage the difficult boundary between life and death, which I discuss further in Section 2.10.

## **2.7 Older people as stigmatised/marginalised members of society**

In his work on stigma, Goffman (1959) considers the ways that identity can be faulty or ambiguous, and presents a theory of how people manage their spoiled identity. In particular, he writes about the moral obligation we have, as members of society, to protect our own face and that of others. Featherstone and Hepworth (1991) suggest a shift from the rigid model of the stages of the life course to one in which the hierarchies have been deconstructed to produce more of a process of development through the life course and alongside this the possibility of individual worth, regardless of age. They cite famous older people in society, such as film stars and politicians, who represent embodied success and a positive image of ageing. However, this change brings penalties associated with the loss of faculties and, in particular, the loss of bodily control. They also cite Elias' (1994) concept of 'bodily betrayal' to argue that, '(D)egrees of loss impair the capacity to be counted as a competent adult' (p. 376). In this thesis I have drawn upon the ideas from Goffman, that people who are stigmatised have to manage discrediting information about themselves. Perhaps it is the case that the admission of older people in society into institutions is, in part, a practice in response to stigmatised people but it does not follow that residents and staff in care homes for older people share the same view of themselves. Therefore, this undifferentiated association between old age and stigma was too generalised and Featherstone and Hepworth's recognition that penalties are more likely to result from the combination of old age and loss of control were more helpful.

### **2.7.1 Institutions as sequestered places**

In the 1960s there were many concerns about the extent to which people in institutional care suffered the consequences of a loss of autonomy and the dependency that this created. The induced dependency hypothesis, as this was called in the literature was the outcome of studies by Townsend (1962), Goffman (1961) and Booth (1985), which

resulted in recognition of the dangers of institutional life. The actions that resulted from these studies to counter dangers of institutionalisation, had a direct impact on the culture of care homes of older people as well as other institutions. It is particularly relevant to this thesis that the focus on 'rehabilitation' has produced a particular status of 'living' for care home residents. I explore the detail of this in Chapter 4. Indeed in this thesis, the production of 'death and dying' as the oppositional category of 'living', impacts upon the way that death in care homes is produced as well as the context within which 'dying' is interpreted.

Goffman's (1959, 1961) study of the sociology of everyday life is particularly relevant to a sociological understanding of what happens to people in institutions and the meaning of their behaviour (1959–1961). His theoretical ideas encompass the nature of the self and social life and the organisation of experience. Goffman's (1961) study of institutions complements Townsend's (1962) seminal study and provides an explanation of what happens to people when they enter such places. He argues that the main features of social life that produce and sustain people's identity are lost when they enter 'total' institutions in that 'social arrangements regulate, under one roof and according to one rational plan, all spheres of institutional life' (1961, p. 18). Willcocks et al (1987), discuss the degree to which institutional living structures the routines of daily life and argue that any adaptations which residents make to residential life will be varied and multi-faceted because of the functional, personal and symbolic impact of environment on quality of life. This is part of the dimension of social death discussed in Section 2.4.4. I return to his ideas here to highlight the way that it is a feature of institutions. I will argue that death is part of the production of care homes for older people; both as an end product and also as a performance. The tensions between the response to this series of losses that result from institutional life through intense rehabilitation and the reality that residents are likely to be much closer to death, as a consequence of delayed admission to a home, makes the role of the institution highly relevant. According to Goffman (1961), people suffer a series of mortifications of the self on admission to total institutions. The

series of activities that 'rob' people of their role(s); instil in them a belief that this institutional life is forever. The way in which Townsend presents his form of 'structured dependency' (1986:15) suggests that the dependency is more symbolic than real and serves a purpose of legitimating a lack of access to equality of status (1986:32). This is a more subtle form of criticism of the quality of life for older people in institutions and raises questions about the symbolic elements of the quality of dying to which I return in Chapters 5 and 8. Goffman places the admission to institutions as a rite of passage into a world in which the process of social control and restrictions remove people's self determination, autonomy and 'adult competency'. Goffman goes on to note that as 'inmates' become increasingly institutionalised they begin to regulate themselves and their own behaviour. The similarity between this and Bentham's (1995) notion of the panopticon is striking.

The technological design of a prison as a place designed for unseen surveillance is also relevant to the public spaces of care homes where residents are 'on view' but not necessarily aware of being seen. Certainly, part of the nature of institutional life is the extent to which inmates are observed and these ideas helped me to consider the level of surveillance of 'living' residents and also the increase at the time of death when dying residents disappear from living spaces. However, the main point of the notion of the panopticon is that, if people do not know whether or not they are being watched, they are likely to assume that they are and behave in a self-regulatory manner. Again this connects to Goffman's ideas and helped me to explore the way that residents co-construct what it means to be 'living' and what it means to be 'dying', according to the way in which these states are defined by the institutions.

## **2.8 Managing boundaries: the tension between living and dying**

The move against institutionalisation that arose from the writings of people like Goffman and Townsend resulted in a changed focus in these settings to counter the induced dependency hypothesis. It is possible that with such a high premium on the need to 'keeping residents going' as Hockey (1990) discusses in her study of death and dying in care homes, the boundary between 'living' and 'dying' takes on even greater significance than in other settings. Producing residents as 'living' makes 'dying' and death an even more taboo state. Whatever the level of disclosure about death and dying, there is usually a point at which people can be defined as dying. The criteria by which this definition is made are usually based on medical measurements. These measurements can be made either prospectively or retrospectively.

While it is the case that concerns about the quality of life are significant and often justified, for older people who might offer a complex picture of multiple chronic conditions associated with ageing, this process is likely to be complicated. I would argue that the high level of investment on rehabilitation and quality of life adds to this complexity in care homes. The points made in Section 2.3.1 by Moxley et al (2004) that residents with the highest dependency needs are most likely to die soonest suggest that the any division between living and dying will be difficult to make in residents who have high levels of dependency.

Glaser and Strauss's (1965a) study of death on hospital wards drew upon van Gennep's rites of passage (1960). They found that there was a high investment made by staff in being able to predict death so that procedures and tasks could be undertaken and death itself managed. Glaser and Strauss' term 'dying trajectories' describes the course and shape of dying. They claimed that not only was it possible for medical staff to be able to read signs that were predictors of death, but also that there is a vested interest by everyone involved to predict when deaths might occur. However, these predictions were

complex, needed to be updated and even 'renegotiated'. For example, they categorised predictions into three main types. First, they found that it was possible to be virtually certain about when the death would occur. Second, for those patients for whom there was less certainty about the time of death, it might be possible in the future to establish a time when there could be certainty. The third and final category and the one that staff found most difficult to cope with, was that in which the time of death was 'uncertain' and there was no clear time when any certainty could be established. In other words there were patients for whom it was unlikely that staff would be able to predict the time of death.

Part of the need to be able to predict death derives from a desire to produce a 'good' death. Achieving a 'good' death clearly depends upon being aware of the imminence of death and the opportunity for the dying person to express their wishes as well as the capacity for care staff to be able to carry these out.

## **2.9 Managing death in care homes for older people: rituals to sustain the perceived vulnerability of the life/death boundary**

In this section I discuss how a special case is made for the management of older bodies and how the ways in which they are managed signals their difference from younger bodies. The people who are most likely to be admitted to care homes are those who have been unable to care for themselves and are without the means to be cared for in the community. In care homes for older people the levels of dependency since the 1990 NHS and Community Care Act has been well documented (Komaromy, 2002; Peace, 2003; Sidell and Komaromy, 2003). Above, I referred to the argument by Tulle-Winton (2000) that bodies that are not 'self regulating' become the responsibility of government and other agencies. Ethnographic accounts of the management of bodies emphasise the focus on the physical side of that care. In Twigg's (2000) study of community care she

highlights the way that care staff have to do to deal with the taboo nature of work with the body. She argues that the ambivalence of care work results from this tension.

*It (care work) manages the negativities of the body and the physical aspects of human physicality that modern society has become increasingly intolerant of in the pursuit of modern dreams of autonomy, boundedness and youthful success.*

*(Twigg, 2000, p. 158)*

Similarly in care homes for older people the staff were preoccupied with the physical care of the residents (Komaromy, 2004c).

Julia Lawton's (2000) study of death in hospices exposed the extent to which these 'open' dying spaces were also places that concealed 'dirty' dying. Lawton argues that people dying with cancer who remain in society physically and symbolically represent the more acceptable aspects of personhood. She found that it was much more likely that people who were incontinent of urine and faeces, weeping limbs or other forms of fluid loss that signify 'unbounded bodies', would be admitted to hospices. Furthermore, if these leaking bodies could be rebounded, then people were more likely to be discharged home again than those who remained 'uncontrolled'. It seems that the body that is in decline towards death is particularly problematic when it is 'leaking'. If the ageing, leaking, unbounded body as a container of death is in need of management and containment, it is unsurprising that they find their last refuge in care homes. The possibility of society being able to contain certain forms of dying contributes to debates around social death in a way that captures the reality and the symbolic meaning of dying bodies in need of containment. This makes the matter of old and ageing bodies more likely to be concealed.

The work of Douglas (1984) is key to understanding aspects of the need to keep the body intact and the preoccupation for care staff with the physical body. In her seminal work on the concepts of pollution and taboo, Douglas argues that rules of hygiene are only partially concerned with biomedical dangers associated with dirt. Dirt and defilement carry symbolic meaning and are rooted in the religious order. According to



Douglas dirt is 'matter out of place' and responses to 'dirt' which carries the danger of pollution, is ritualistic. Ageing, decaying, leaking, smelly and confused bodies might comprise what Douglas refers to as matter out of place (1984).

*Death has long been perceived as a dirty and polluting thing. As Lock (1996, p. 235) suggests, 'Whatever form death takes, it conjures up that margin between culture and nature where mortality must be confronted'. Such margins are invested with power yet are potentially dangerous (Douglas, 1984, p. 35) and require management in some way. Such management is 'pulled off' by an appropriate performance which at the same time serves to 'mask' or create distance from the death. The focus on the living, the physical in both performances may serve as this mask. Yet, if, as the data suggests death in both the acute hospital environment and also in a residential home were 'matter out of place', the question remains as to where death has to go to be acceptable.*

*(Page and Komaromy, 2005)*

So far I have drawn on existing literature to suggest that, while death is largely a professional affair, the allocation of medical resources, and attitudes to older people, have resulted in there being the possibility of a different type of end-of-life care for older people which reminds us of its distinctive difference. One of the results of the loss of long-stay NHS beds has been the targeting of more intense care in the community with little left over for those in less need of care. People make the decision to enter residential care for a number of reasons, but the increased trend is for this to be people who are older and frailer, and as such unable to stay at home.

## **2.10 Performativity**

The examples of medical rituals will inevitably involve the need for staff to be able to get things right and give a convincing performance of this, whatever their personal feelings. In applying this idea to 'dying' it seems that the 'impression' is 'managed' according to

routines and rituals that structure how staff members behave. To take the analogy of performance further, it is important to define the extent to which these 'scripts' are often written into organisational procedures and protocols of care homes as codes of behaviour. According to Goffman (1959), the individual is constrained by social scripts and is also a manipulator of impressions. Similarly, Walter (1999) argues that it is as inappropriate for professionals concerned with death, dying and bereavement to be too upset as it is for them to appear to be unaffected.

But behaving in a professional manner is much more than an act according to Goffman (1959). For him, people have a dual identity that comprises the self as a social product (consisting of social roles all of which are loosely integrated) and a real self. One of the consequences of this is that the presentation of self is both ritualistic and moral. The outcome of this is that the self is both socially determined and dualistic, socialised/unsocialised. The self is the mask that the individual wears and also the human being behind the mask who decides what mask to wear. Furthermore, the self is the product not the cause of the 'scenes' that are acted. Making a distinction between the true self and the performing self is also a social act and socially produced. In other words the distinction between role and person is socially framed.

The nature of relationships in institutions is key to understanding what is taking place. Goffman (1961) argues that the impressions that people make seem to be treated as claims and promises that are made implicitly – as part of what Goffman calls the 'creation of the desired impression' (p.243). By this he means that individuals manipulate their efforts in order to achieve certain ends. If it is then the case that observers use impressions as substitutes for reality which means that they fail to detect this manipulation, it follows that those people who are making the impression – the 'observed' – become performers and observers become the audience. All individuals-as-performers are concerned with the impression that they make and need to live up to the standards by which they are judged. This happens in congruence with structures, roles and

relationships in accordance with the social order of the context of the situation and no more so than in institutions. Since Goffman would argue that the 'self' is made up of multiple loosely-integrated social roles then this self is socially determined.

Manning (1992) writes that, according to Goffman (1959), as individuals, we present ourselves in everyday life as if in a theatrical performance. The six principles of the dramaturgy are presented below:

### **Dramaturgy (The presentation of self in everyday life)**

- 1 Performances are concerned with the actors giving convincing performances, in that the audience should recognise the authenticity of their actions and thereby give authority to the performance.
- 2 The social space of a performance involves the separation of a front and back region. The front region is where the performance is given by the team acting in a homogenous way, and the back region is where impressions may be knowingly contradicted. This is an essential feature of maintaining the performance. In care homes bedrooms were the private spaces of the home with communal areas serving as the public spaces.
- 3 Teams are concerned with representing the character of a social situation; individuals do not act alone. In care homes, teams could comprise the homes staff, residents and visitors to the home.
- 4 Discrepant roles involve performers who are at one time performer and at another audience. I was frequently told during the interviews for the commissioned study (Sidell *et al.*, 1997) that care staff were like family to residents who did not have any visitors.
- 5 Communication out of character refers to expression of sentiments that are discrepant with the official performance. This can be either backstage or front stage, if it is the latter it is more problematic, being between audience and performer(s).

6      Impression management involves three key characteristics, which Goffman (1959) describes as defensive practices – of, loyalty, discipline and forward thinking. Protective practices are the audience's way of maintaining the performance by not noticing or drawing attention to any contradictions in the performance and pretending not to see the flaws. Following this, the performer responds to the tact of the audience by modifying the performance. I was concerned to explore the way that the policies and practices of the home might serve to script the performance of care staff, residents and visitors. Also to what extent, if any, loyalty impacted upon the way that dying was produced?

Therefore, according to Goffman (1959), individuals are concerned with living up to many moral standards of the social world. However, there is an important qualification which he makes, performers are not concerned with the moral issues of operationalising these moral standards through their actions, but with the amoral issue of making a convincing impression that these standards are being realised.

Furthermore, if it is the case that behaviour is a performance of the presentation of self, and contains ritualistic and moral dimensions – then a large part of what is acceptable is determined by the expectations of the roles that people occupy. An individual's management of the impression that he or she makes is dependent upon the projected agreement of others. The difference between the person and the role is socially framed in that the intimate self-image is constructed out of the same materials as the projected self.

## **2.11      Summary**

In this chapter I have set the scene for the state of death in care homes for older people. I have drawn on relevant literature in the field of death and dying to argue that the attitude to deaths of older people, while part of the medicalised response that is a feature of western societies, is different to that of younger people. Part of the explanation for this

lies in the way that youth is privileged above old age. I have cautioned against the assumption, however, that it is age alone that gives people their social status. While it is the general case that the deaths of older people are less likely to be postponed and thus will be less medicalised, the betrayal of ageing bodies can signal a more stigmatised attitude to failing ageing people. Combined with a failure of care in the community and the tendency not to medicalise the decline associated with ageing, older people who are admitted to care homes are likely to have more intense care needs and to be closer to the end of the dying trajectory than was the case in the past.

The profile of residents and the increased death rate in care homes makes death a more regular event. However, the expectation to counter induced dependency – reinforced by the inspection and regulation authorities of care homes – means that it is unlikely that death will be a 'visible' part of home life. I have argued that home staff are keen to produce a good death for their residents and that this production is more likely to be for the sake of surviving people than for dying residents. The ageing body in its living state needs careful management and the body, as a container of death, requires particular rituals and performances at the time of death. With the focus on managing death as a timely and natural event, but one that is in danger of contaminating living spaces, there is a premium on being able to give a convincing performance during death and dying.

## **CHAPTER 3**

### **Methodology and settings**

#### **3.1 Introduction and aims of the study**

In this chapter, I describe the ways in which I chose the research methods which I used so that they best captured what I wanted to explore. I explain my reasons for choosing a subtle realist approach within ethnography and move on to consider issues around data collection and analysis that arose from this approach. I provide an account of the methodology literature that helped me to steer a course through some of the ontological and epistemological dilemmas that beset researchers who choose a qualitative approach. The chapter then presents in more detail the components that I selected within ethnography. I discuss other studies that helped me during my approach, my fieldwork and analysis. I then explore the settings in which I made observations and discuss how these were selected. Finally, I discuss issues of access to homes, participant observation, including ethical considerations and leaving the field.

In the introduction to this thesis, I discussed the special nature of the relationship between the thesis and the commissioned study (Sidell *et al.*, 1997) and how it was, during the interviews with heads of homes in the commissioned study, that I began to develop questions that I wanted to explore and how I became aware of what seemed to be contradictions in their accounts of death and dying in care homes. I also explained how this provided me with the opportunity to refine my thesis

questions more precisely prior to entering the field. Starting from the position of staff rhetoric, I wanted to go on to explore practice. Therefore, the emphasis in this thesis is on the behaviour of the staff in the institutions of care homes. This reflects the way that the power of these practices of care staff shaped the experience of 'dying' for the home residents. The following issues for exploration based on the findings from interviews with heads of homes summarise the tensions that I wanted to explore via the thesis and which arose from these interview 'contradictions'. Therefore, I wanted to:

- compare what happened at the time of death and dying and how this was different from what heads of homes told me at interviews in the commissioned study, and then
- explore how 'dying' was produced in the care homes as different from 'living'.
- explore what happened when residents were dying and around the time of death through direct observations.

I had the opportunity to explore these areas and in order to consider how to best capture what was happening, I turned to the literature on ethnography.

### **3.2 Choosing an ethnographic approach**

I wanted to find out how people constructed meanings and what these meanings were in relation to my research questions. I also wanted to see what was taking place at certain times and within the context of the care-home setting. I chose an ethnographic approach because its flexibility offered me the potential to find answers to the above questions. Blumer (1969) argues that if we want to understand the world from the point of view of the actors in it – then we have to *see* the world from their point of view. Participant observation offered me the possibility of seeing what was happening, noting the context and being able to talk to those people involved,

including residents, home staff and any visitors about their understanding of what was happening. Brewer (2000) defines ethnography as:

*(...) the study of people in naturally occurring settings or 'fields' by methods of data collection which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally.*

*(Brewer, 2000, p. 10)*

Brewer further describes ethnography as:

*a style of research that is distinguished by its objectives, which are to understand the social meanings and activities of people in a given field or setting as well as its approach, which involves close association with, and often participation in, this setting.*

*(Brewer, 2000, p. 11)*

Thick description has been defined as '(...) detail, context, emotion, and the web of social relationships' (Geertz quoted in Denzin, 1989, p. 83). This can only be achieved if people are studied in 'naturally occurring situations'. Geertz (1975) first used the term 'thick description' to describe the way in which ethnographers provide close access to lived reality, by providing very detailed descriptions of events which takes account of the potential significance of every detail, rather than prejudging aspects as being insignificant or not contributory.

However, it is not straightforward to claim that I would be able to represent the reality of death and dying in care homes for older people using the participant-observation method. There are many debates around the extent to which it is possible to be able to represent reality. Clifford and Marcus (1986), discuss 'realities' as rhetorical devices, while Smith (1984) claims that there are as many realities as there



are people and Atkinson (1990) discusses the way that reality is constructed and reconstructed through ethnographic accounts. Gilbert (1993) describes the type of knowledge that researchers derive from participant observation as 'introspective' in that it involves the researcher in making connections between the world of participation and one's own personal experience. This crisis of representation that reflects the realism versus relativism debates within post-modernism, affects the choices that researchers make about research methodology. Furthermore, debates about the crisis of representation challenge the ability of any research method to be able to present a close and realistic description of any social reality. Thick description has been positioned as a 'reassurance' of the validity of research by the ethnographic approach but the extent to which reality can be captured involves both philosophical and ontological dilemmas and it is something with which I had to struggle in order to understand what I would be able to make claims about.

The further I entered into the methodological debates that have arisen from this crisis of representation, the more I had concerns about the extent to which participant observation could be a 'naturalistic' pursuit and one in which the researcher did not affect the context. I was aware that what I captured would be compromised by my presence and later in this chapter, I consider the potential impact of 'being there' upon what I wanted to observe. But here, I want to make the point that the only possibility of being able to capture the events that occurred at and around the time of death was to be a participant in what was taking place; in other words to be there.

### **3.2.1 What claims is it possible for researchers to make?**

The contested nature of truth also presents dilemmas about the status of research findings and what claims it is possible to make for any researcher. Seale (1999) suggests that there is a middle way between the post-modern position of the multiple

forms of reality, each of which is uniquely constructed, and the notion that there is a fixed reality 'out there' that it is possible to be able to represent accurately. This middle ground can take the form of a conversation between researchers, in which research findings form sections of this conversation. Altheide and Johnson (1994) argue that:

*(R)esearchers should report how they gained access to the research setting, how they presented themselves within it, including details of the roles taken, the degree to which researchers believe that trust and rapport were achieved and an account of any 'mistakes', misconceptions, surprises. Ways in which data were collected and recorded should also be included, as well as lists of the various types of data available to researchers and coding and any other analytic procedures.*

*(Altheide and Johnson, 1994, p. 494)*

The process of researching and writing a thesis, allowed me the opportunity to share my field work notes with other academics. However, while much of what is included in the quote above is covered in this chapter, it is unusual for research findings to be open to this level of scrutiny. In this thesis I have drawn heavily on 'subtle realism' that Hammersley (1992) presents as a middle way through the dilemma of being able to convey the meaning of reality as discussed above. His account of 'subtle realism' defines research as plausible when 'any truth claim is likely to be true given our existing knowledge'. Therefore, while as Hammersley claims, no knowledge is certain, he argues that a reality exists that is independent of the researcher and about which it is possible to make reasonably accurate claims. This perspective seemed to offer me the best way forward and accommodated my own view that it is valid to offer an interpretation of the truth about something, while recognising that there are other versions. This approach suggests that it is still important that the researcher includes, or at least recognises, that he or she is part of the research process. This recognition

is more generally referred to as being a reflexive researcher. Steier (1995) describes reflexivity as:

*(...) a turning back onto a self, is a way in which circulatory and self reference appear in inquiry, as we contextually recognise the various mutual relationships in which our knowing activities are embedded.*

*(Steier, 1995, p. 163)*

In Chapter 1, I discussed the way that my personal biography was an integral part of the research process. Not only was this the motivating force behind my need to explore this area of research, it was also the lens through which I viewed what was taking place. Given the nature of the research and the ways in which death and dying are constructed as sensitive issues, it is also appropriate to consider the ethics of participatory fieldwork, both from the point of view of researching sensitive issues and my role in that construction. Henderson and Vesperi (1995) argue that it is necessary to provide this detail in a way that makes the unfamiliar familiar, while at the same time conveying the special circumstances of the situation. I saw this as part of my task and again this is addressed later in this chapter.

I would agree with Hammersley (1990) who claims that no knowledge is certain, but that there are phenomena that exist independently of researchers and it is possible to be able to make knowledge claims about them. However, if all knowledge is based on assumptions and human constructions, then, according to Hammersley, researchers need a new way of judging the validity of truth that is based on the plausibility, credibility and evidence tests of accounts. In the end, for Hammersley, what seems to be most significant is the extent to which research contributes to existing knowledge and can solve social problems, or at least improve the position of those being researched if they are in some way disadvantaged. Furthermore, if researchers want their findings to contribute to a change in practice then adding to the information about particular settings will make that a more realistic possibility. In

the following section I describe the detail of the approach that I took and relate it to my fieldwork in care home settings. Next, I explore the detail of subtle realism and how it relates to my research for this thesis.

### **3.3 The 'subtle realism' approach**

Hammersley (1992) argues that in ethnographic research:

- 1 the focus is normally on a single setting or group and is small-scale;
- 2 data are collected by various techniques, but primarily by means of observation;
- 3 people's behaviour is studied in everyday contexts rather than under unnatural or experimental circumstances created by the researcher;
- 4 data collection is flexible and unstructured to avoid pre-fixed arrangements that impose categories on what people say and do;
- 5 analysis of the data involves attribution of the meanings of human actions described and explained.

I now take each of these five aspects in turn and relate each to my own fieldwork.

- 1 The focus is normally on a single setting or group and is small-scale, and**
- 2 data are collected by various techniques, but primarily by means of observation.**

Care homes for older people comprise a group of settings in which it would be possible for me as a participant observer to focus on the events that surrounded death and dying. Designing the study in this way, would also provide a comparative model so that it would be possible to see if there were shared patterns and understandings that were associated with death and dying in other care homes as well as exploring any differences between them. Using

eight homes for fieldwork meant that I could use homes from different registration type, size and setting, as well as being able to draw on different types of data to provide a richer picture and to consider the relationship between institutional context and individual home 'culture'.

### **3 People's behaviour is studied in everyday contexts rather than under unnatural or experimental circumstances created by the researcher.**

Brewer (2000) argues that:

*People are meaning endowing, in that they have the capacity to interpret and construct their social world and setting rather than responding in a simplistic and automatic way to any particular stimuli.*

*(Brewer, 2000, p. 34)*

This interpretative approach was the one that was most helpful to me in considering how best to search for answers to those questions that I wanted to explore. Brewer states further:

*(P)eople live in a bounded social context, and are best studied in, and their meanings are best revealed in, the natural settings of the real world in which they live'.*

*(Brewer, 2000, p. 35)*

From this position it follows that, in order to gain knowledge of the social world of care homes, I would need to hear the accounts of actors and also to observe their behaviour at key moments such as when residents were defined as 'ill' or 'dying' and what happened at that time.

Clearly being present in the homes as a participant observer meant that there was the possibility of creating a different reality. However, I would argue that context is a more complex phenomenon that arises at different levels of

the individual, the institutional and the social (Komaromy, 2004b). Wallman (1997) notes that connections which comprise past experience, present prejudice and future purpose, are part of context and not static but a process, and difficult to capture. I was aware that my presence was likely to influence some dimensions more than others. So that for example, at the individual level, and in individual encounters I had more potential to change the reality, through inviting staff and residents to talk to me about their views and understandings, than to influence events at the institutional level, which included the routines and practices of homes such as feeding, washing and dressing residents. I argue that the shifts which staff worked and their ways of working were robust and unlikely to be changed by my presence. Likewise at the social level of context, I would locate such things as the policy and practices associated with where older people are cared for, the economic and ideological approach to ageing. Context, therefore, does not only provide interesting background information that makes more sense of events. It also arises at several levels and in several forms; some of which are more subject to change than others. Therefore, I anticipated that I could expect to see greater differences between homes in some areas than in others.

It was more likely that there could be a rift between what I observed and how I recorded what I observed. Therefore, I needed to be careful that my field notes were as detailed and close to what I observed as possible in order to minimise my own interpretation of what was happening and this is what I turn to next.

#### **4 Data collection is flexible and unstructured to avoid pre-fixed arrangements that impose categories on what people say and do.**

Williams and May (1996) define research that occupies the middle ground between relativism and positivism as being research that 'constructs transitive

objects' (1996, p. 85). Resisting the temptation to set up categories prior to the research allowed for any observations to be interpreted in such a way that was fluid rather than being fixed and rigid. This is also relevant to point five below. This position of holding onto a philosophical scepticism that considers the social world is one that is constructed through social beliefs and practices. Furthermore, Seale (1999) suggests it is possible to find some middle ground by understanding the debate as being a conversation stimulating methodological awareness among researchers, rather than laying foundations for truth.

Being open and taking an approach that questioned assumptions and shared understandings, was clearly something that I would need to be ever vigilant about doing. During interviews with heads of homes, he or she presented a specific view of what it meant for a resident to be 'dying' in a care home. While this rhetoric is what I wanted to explore, I was also aware that in 'seeing for myself', I needed to be aware of the role the head of home's practice would play in what I observed and how this view might mediate my own observation. One way of challenging some of these expectations and preconceived ideas was through the way that I documented my field notes, for example, by separating out direct observations in the field, reported speech, and a summary of what people told me from my own reflections and interpretations of what was happening. From talking to colleagues who had used a participant-observation method, I understood that writing up field notes was extremely time consuming and I was aware that I needed to be prepared for this type of practical demand as well as being available to observe the events as they happened. Hammersley's (1992) points relate in part to this, but it is also about approaching the field with an open mind and being ready to adapt research plans to what is found there. Given all of these qualifications, I felt confident that I could collect data in the homes according to this approach.

This study would be distinctive in allowing comparisons between observations in several different homes, which would help to serve as a constant challenge to pre-conceived ideas and offer up the possibility of new categories.

## **5 Data analysis involves attribution of the meanings of human actions described and explained.**

Not only do the observations of what is happening in the home need to include an account of the context, but also, the researcher needs to be aware of this during data analysis. Hammersley and Atkinson (1995) argue for researchers to be reflexive by setting the data against context. Each situation is to some extent context dependent. A fuller understanding of the context in which events occur provides a much richer explanation of what is happening. Brewer (2000) extends this position, to one in which the ethnographer aims to:

*(...) be explicit and open about the circumstances that produced the extant data, recognising that ethnographers (like all researchers) are within the social world they seek to analyse. Since there is no perfectly transparent or neutral way to represent the social world, reflexivity on the part of the researcher assists in identifying the contingencies that produced his or her portrayal of it, so we should claim no more for the account than what it is, a partial, selective and personal vision'.*

*(Brewer, 2000, p. 48)*

Brewer argues further that there is no distinct stage of analysis within ethnography, but that it is part of a continual process. This process of analysis in the field and analysis after fieldwork is further discussed later in this chapter.

Adler and Adler (1998) argue that a researcher's own experience and attitude in the field become part of the data, since he or she participates in the field. As



a participant observer in the field and as someone who would be involved in the meaning-making aspect of the data collection and interpretation, it was important that I reflect on my role in that process. I have set out above how my field notes would accommodate different types of observation. However, I still argue that, while I recognise that my presence had the potential to change certain dimensions of context as discussed in Section 3.3, the nature of the research meant that my presence would have varying degrees of impact and therefore the potential was for this to be greater at the individual level of context than at the institutional or social level. If I was going to use an interactionist interpretation of what was taking place, it was important, too, that I was aware of how I wanted to present myself in the home setting. This aspect of my own presentation of self was made up of what I brought to the fieldwork (discussed in Chapter 1), as well as how I behaved in the field.

### **3.4 Degrees of participant observation**

The term participant observation has a broad range of interpretations. According to Gold's (1958) categorisation of degrees of participant observation, I would locate myself as mainly 'observer-as-participant' rather than being more fully integrated into the role of participant-as-observer or non-participant observer. Furthermore, in Adler and Adler's (1998) typology my intended involvement would give me what they call 'peripheral membership'. I claim this position because, in an area which is not often researched, it was going to be difficult for me to be able to explain my role in a way that was culturally familiar to the heads of home, as gatekeepers, as well as the staff and residents. In contrast, care homes are frequently visited by care home registration inspectors and I had concerns that I would be seen as someone making value judgements about the quality of care in the home. It seemed likely that the nature of the observations that I would make would be the outcome of the relationship between

myself and the people in the field. In turn, this was likely to differ between care homes and between encounters within them. In other words, my role would be framed by the relationship with the home and defined at the level of individual relationships within each home.

There is a human relations side to research that goes beyond ethical considerations. For example, de Laine (2002) argues that a researcher takes into the field what she calls a 'bundle of roles' and that researchers draw upon a repertoire of roles, depending on the situation. From a mainly ethical point of view, I assumed that my training as a counsellor would help me to listen effectively and in a supportive way at times of more sensitive disclosure during the fieldwork. Furthermore, talking to an individual about sensitive issues and encouraging him or her to talk about loss and the possibility of their own impending death, would require me to be able to offer some form of support<sup>1</sup>. I also knew that I would need to be able to challenge ideas in a non-judgmental way so that people would be able to explain the meaning behind their accounts. In the interviews with heads of homes during the commissioned study, the time that I could spend with them was limited and I needed to cover a wide range of areas related to death and dying in that home. I had learned from this that I needed to balance focused and probing questions against what people wanted to tell me and in the time we had available. This experience led me to consider two key aspects of entering the field. First, I needed to be flexible about time and second, I needed to learn from similar research. Part of my own support came from my PhD supervisors and colleagues conducting research into death and dying. Most significantly, however, I used a professional counsellor to provide clinical supervision during the fieldwork period (this is discussed further in the conclusion to this thesis). I would argue that

this was an essential part of being able to understand the contribution of what Wallman (1997) would refer to as (my) 'past experience and present prejudice' (see Section 3.3 above).

### **3.4.1 Other studies into death and dying**

I drew on literature from three key death studies to help me to anticipate being in the field and its appropriateness to what I wanted to capture in terms of data.

#### *The physicality of being a participant*

First, Hockey's (1990) study of death and dying in a residential home offered an understanding that prepared the ground for me. Her study involved one residential home (and a hospice) and it was clear that there would be many similarities with my own fieldwork. Hockey argues that participation is about joining in with rather than talking about experience. In particular, the way that staff managed 'bodies' involved the participant in the physical experience of body work. This in turn affected the bodies of staff in that it had a direct impact upon them, so that for Hockey, part of the experience of participation was to experience this physicality. This would help me to consider bodies as communication (Komaromy, 2004a) and the way in which the physicality of caring for bodies by staff could inscribe this caring on the bodies of the staff, through their tiredness and any physical changes that this work might bring. Hockey argues that this is something which researchers experience, so that not only do they see and hear about the physical side of staff caring for ageing bodies with the use of their own bodies, but also, as the researcher they experience this for themselves.

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<sup>1</sup> From an ethical point of view, I would argue that giving people an opportunity to talk about the subject of death was morally permissible, if this was what the resident indicated that he or she wanted to do.

It was my intention that I would be as involved with the care of residents as far as I was allowed to be but there were potential limitations to this care. First, the relatively short time I spent in each home meant that I would be less likely to become accepted as part of the staff group than if I devoted the entire 12 months of the fieldwork to one home. Second, I had concerns about what I would be participating in. For example, my visits during the interviews for the commissioned study revealed a division between two worlds, the staff and the resident world. I wanted to be able to see the world from the residents' perspective as much as possible and it was my intention that I would spend time sitting with them, and eating with them. However, the focus of my exploration was on the way that 'dying' was produced, and as I explained in Chapter 1, it was most likely that the care staff would be the dominant actors in this production.

### *Explaining the participant-observer role*

The second key study is an ethnographic account of the funeral industry by Howarth (1996) who discusses the 'outsider' status of the researcher. I argued in Chapter 2 that, while care homes are physically situated in the community, they are marginalised as containers of ageing, decaying and dying bodies. Age and death combine to produce a 'tabooness' that would seem to equal the outsider status of death workers in the funeral industry. I have drawn on Howarth's work, not just for her interpretation of an interactionist perspective, but also to help me with my role as participant observer. More relevant to my proposed fieldwork is the issue that Howarth (1993) raises about giving a clear account of what is being investigated through an 'outline of the objectives and methods'. She makes the point that ethnography is very difficult to explain to people who are not familiar with the 'culture' of research. The funeral industry has been variously investigated for sensationalist interest and Howarth had to convince the gatekeepers of the settings used in her study that she was 'sincere'. I found the similarity quite striking in that care home

settings are used to being observed specifically to uphold standards of care and a home can lose its licence if it does not meet required standards. It was important that I was able to give an account of the reason for my visits that would be comprehensible and disassociate me from the role of inspector. I have described the way that heads of homes welcomed my enquiry into a neglected area. But I needed to explain how, in my study within a study, I was enquiring into the way that staff provided end-of-life care and also what happened when a resident was dying and at the time of death.

### *Managing professional understanding*

The third study, by Seymour (2001), is of an intensive care unit and offered me an insight into how she managed prior knowledge acquired from her role as a nurse, alongside adopting the stranger's perspective in this setting. While Howarth was a stranger in a world of the ritual in the funeral business, Seymour had to challenge her own preconceived shared understanding of what was taking place with the nursing staff in the intensive care unit. My own position was somewhere between the two. As a nurse, I also shared an understanding of the rituals associated with death and dying in an institutional setting, albeit a hospital setting. And I needed to challenge my own taken-for-granted understandings of death and dying. I had not worked in a care home and it was a strange and alien setting for me.

### **3.4.2 The power of the role of the researcher**

This also begs the question of how clear the study participants were about my role and what I was doing with any data that I collected. It seemed probable that I would be regarded differently in different homes and also within them by different participants. The issue of role, and the potential power carried by that role, is very pertinent to the culture of care homes. I knew from the early interviews with heads of homes that there were clear role boundaries and concerns about what it was

permissible for certain care workers to do. Role, power and status were aspects that I would want to investigate within the ways in which death and dying was produced. The hierarchical structure and the tension between institution and home are features of the institutional context of the homes and something that I will refer to in the data chapters that follow. In general, my first impression was that care homes were reminiscent of hospitals during the 1960s and 1970s. As a methodological point, it seemed that it was going to be difficult for heads of homes to be able to position me within the existing hierarchy and that I was always going to stand out.

I wanted to be able to observe death and dying first hand in several different care homes and methodologically, this presented problems that arose at a practical and pragmatic level. The sensitive nature of death and dying would call for particular considerations in relation to what sort of data I could and should collect. Lawton (2000) in her ethnographic study of dying in a hospice and the way in which dying impacts on social identity, argues that it is inappropriate to do more than observe when someone is dying. She writes:

*Formal interviews not only seemed to me to be too obtrusive to many patients and their families; in a substantial number of instances, they were simply not viable.*

*(Lawton, 2000, p. 30)*

It would seem to be important that any enquiry into identity such as Lawton's, would require accounts from those people whose identity was being explored. Likewise, in my exploration into what happens at the time of death, I wanted to hear what those residents who were close to death had to say about the experience. What did they understand and what had they been told? In some ways, what I was trying to unpack was the potential arbitrariness of the status of 'living' and 'dying' for people who were already very old, frail and suffering chronic illness. While being able to hear about the experience of residents would not involve me in making artificial distinctions between

specific 'living and 'dying' categories, as with Lawton's fieldwork, when people were very close to death it would seem to be entirely unethical to question them about what they felt in order to get data from them for my study. That is distinct from being there and hearing what people wanted to tell me. I could only hope to listen to those who volunteered information to me.

### **3.5 The purpose of this type of research**

I have argued in Section 3.2.1 that there are issues and debates about the nature of reality and the possibility of being able to capture something close to a separate reality from that which is constructed through the research process. It follows that the nature of my enquiry was an important part of the research data. For example, in the research interviews that were conducted in the commissioned study I followed a research schedule that directed the topics for discussion. It is from these answers that I noted the potential gap between their rhetoric and the practice in care settings, as I have discussed in chapter 1, and which formed the basis of this enquiry. I would argue that the nature of what I wanted to investigate was in part, shaped by my approach to this thesis.

I have also argued that I would not have been able to recognise a potential gap, between practice and rhetoric without being in the privileged position of being able to hear so many accounts about death and dying. I now discuss the settings of the homes from which I collected my data and the methods that I used.

### **3.6 Settings**

In this part of the chapter I will introduce the homes in which I was a participant observer, discuss how the eight homes that were used for participant observation were chosen, the negotiation of access with the heads of those homes and provide a profile of the chosen homes. I will then go on to discuss the process of participant

observation and some of the problems I encountered in negotiating this role and how these were resolved. Finally I will describe how I analysed the data and end with a summary of the key points.

### **3.6.1 The study homes**

The table on the next page provides details of the eight sites in which I conducted participant observation. They include information on the type of registration, the location, size, occupancy and the length of time that I spent in the home in weeks and days. For example, on average I spent eight hours each day in a home and I covered all of the shifts that the staff worked in the homes but did not work the same shifts throughout, preferring instead to be able to capture what happened when shifts changed.

During the fieldwork, homes for older people were categorised according to seven types of registration. The status of ownership was either, private, voluntary or local authority (some of the voluntary homes had a few NHS beds although this was exceptional) and the type of care given could be nursing, residential or a combination of both in dual registered homes. It was possible for homes to combine the two sets of categories listed above, although local authority homes were only registered as residential.

The names of the homes have been changed and in any reference to homeowners throughout the thesis, I have used pseudonyms.

## **3.7 Selection of homes**

In order to explain how I selected the above homes for this thesis, first I need to put the selection into the context of the commissioned study, described in Chapter 1. In the commissioned study the research team, of which I was the full-time researcher, used a multi-method approach that incorporated the collection of both quantitative



**Table 3.1 The features of fieldwork homes and period of participation**

Pseudonym <sup>a</sup>	Locality <sup>b</sup>	Beds/Size	Type by registration	Period of observation <sup>d</sup>	Sex		No. over 85	No. of staff/ 24 hours
					F	M		
St. Mary's House	NW – Urban	(70) – large	Voluntary – Residential Roman Catholic Convent	8 weeks/28 days	65	5	50	15
Peace Haven	NW – Urban	(12) – small	Private Residential	5 weeks/14 days	11	1	10	7
Seaview House	NW – Urban	(12) – small	Private Residential	3 weeks/15 days	7	5	9	6
Church House	NW – Urban	(28) – medium	Private Residential	6 weeks/20 days	24	4	22	6

Regis Home	WM – Urban	(35) – medium	Private Nursing	5/6 weeks–24 days	26	9	25	15
Autumn Lodge	WM – Rural <sup>c</sup>	(40) – large	Local Authority	3 weeks–12 days	27	10	20	12
Poplar Court	WM – Urban	(24 + 1) <sup>e</sup> (respite) medium	NHS and Vol	4 weeks–16 days	12	12	20	12
Victoria Care Home	WM – Urban	(23) medium	Voluntary/Health Care Trust	5 weeks–17 days	13	7	10	15

<sup>a</sup> The names have been changed, but the location, size and type are real.

<sup>b</sup> NW – North West, WM - West Midlands.

<sup>c</sup> Rural included the coast of the North West (Seaview).

<sup>d</sup> The period of observations shows the time period in weeks and the total number of days I spent doing observation.

<sup>e</sup> Poplar Court had one respite bed to provide relief for full-time unpaid carers.

and qualitative data. In Stage 1, a postal self-completion questionnaire was sent to the heads of 1,000 homes in England in order to collect demographic data about the patterns of death in a range of homes in three distinct areas of England: the North West, the West Midlands and the South East. The returned questionnaires from homes (412) provided a sampling frame for a more detailed study of the management of death and dying in care homes for older people. From this frame we selected between 30–35 homes in each of the 3 distinct regions and arranged to interview the heads of homes in the home setting. I conducted all of the interviews in the North West and the West Midlands and several in the South East, which comprised a total of 84 out of 100.

In the commissioned study we were aware that there were features such as type of home, locality, and size that would potentially impact upon the ways in which death and dying care could be managed. However, some of these variables were so complex and interdependent that during the analysis of the interview data, it was difficult to be able to attribute one variable to any significant differences between the homes. For example, I assumed that because of their lack of staff with a formal nursing qualification and the limitation that this might place upon terminal care provision within residential homes, residential homes were more likely to transfer residents out of the home for terminal care than were nursing homes, which were required to have at least one member of trained staff on duty at all times. But on analysis of the data from the commissioned study there was as much variation within nursing homes in this respect as there was between nursing and residential homes. It follows that, in this thesis, the variables within homes were as great as those between them, and they have not been discussed as making a significant difference to what happened during death and dying in homes. The variables that influenced my choice of home for this thesis were size, layout and location of home. I consider each in turn below.

**3.7.1      Registration of homes by type**

The following table summarises the seven types of registration:

**Table 3.2   Summary of registration type**

<b>Private</b>	<b>Voluntary (includes some NHS beds)</b>	<b>Local Authority</b>
Residential	Residential	Residential
Nursing	Nursing	
Dual-Registered	Dual-Registered	

Homes that were designated as ‘nursing’ were much more likely to take residents with nursing needs on admission than residential homes, and therefore, to have a population of residents who were frailer and more likely to die, than residential homes. However, from talking to the heads of home at interview, it was particularly interesting to note that in all types of homes the condition of the resident on admission to the home could be very different from their condition later on and this was a cause for concern. For example, residents in nursing homes could improve and no longer be considered in need of ‘nursing’ care and unsuitable for this home. Conversely, residents in residential homes could deteriorate and create dilemmas about the need to transfer them out of the home, possibly for terminal care.

**3.7.2      Size of homes**

Home size could be measured in several ways. First, the number of residents who lived in homes in England ranged between one and five hundred (Laing and Buisson, 1994, 1995) But there were more typical home sizes and for the purpose of my

selection, I classified them into working definitions (Sidell and Komaromy, 2003).

These are small, medium and large and the range of each includes:

- small – between 4 and 12 residents;
- medium – between 12 and 24 residents;
- large – more than 24 residents.

It is more likely that in a larger home the number of deaths per year would be higher than in smaller homes. When I talked to the heads of smaller homes at the interview stage in the commissioned study, they told me that death was something that had a great impact upon the home because they were not used to death and dying. Some of the heads of homes further elaborated this as something they found difficult to get used to and compared themselves to hospital staff whom they claimed as 'used to death and dying'. I wanted to be able to see what this meant in terms of what people did at the time of death and to be able to contrast that with the larger homes in which death was a statistically more regular event.

Size in terms of number of residents, also mattered because there was a requirement for the registration of homes that they have a particular minimum ratio of staff per resident. The classification of homes into types also affected this requirement so that in nursing homes the ratio of staff member to resident was lower than in residential homes. I wanted to explore how the number of staff working in the home impacted upon the way that death and dying was managed through the allocation of work tasks. For example, in terms of the way that staff were allocated to care for residents, was the care of dying residents seen as more 'important' than the care of those residents who were categorised as 'living'. More specifically, in homes in which there would be only one member of staff on duty at any time, then clearly being able to lift or change a resident's position was limited. This was also more likely to be the case at night.

The physical size of the home was also potentially significant in terms of death and dying and at the interview stage of the commissioned study I noted that the physical size and the layout of the home seemed to affect the way death and dying was managed. For example, the physical closeness of residents to each other in public spaces; the way that people who were unable to move independently and were moved around the home; their visibility and the ease with which staff could move people were all potentially significant aspects of what I wanted to explore when someone was dying and after death. Furthermore, I noticed that homes that were physically large and which housed more than 35 residents were divided into units. Effectively this meant that there were several homes within one home. I wanted to explore what this meant in terms of how death was managed and whether these smaller units shared similar features with small homes and what the differences might be.

Within my three loose categories of 'small', 'medium' and 'large' there were several differences that would serve as contrasts. I will now consider each of these in turn.

### *Small homes*

It is the case from the demographic findings in the commissioned study (Sidell *et al.*, 1997) that most residents of all sized homes were likely to have lived in the home for between two and five years prior to their death. Furthermore, the importance of providing a 'home for life' for the residents was something that the heads of home were often at pains to stress at interview. The heads of small homes were more likely to talk about the residents and staff as being like 'one big family' than those of larger homes. As well as exploring what this meant, I also wanted to explore the extent to which the head of small homes might have a more personal relationship with and interest in the residents and if this impacted upon the way that they managed death and dying. For example, Seaview House and Peacehaven were both private homes

with fewer than 12 residents and where the homeowner was also the head of home. Both Mrs. Stoney and Lin Brown, the respective owners, lived in part of the home and they were present in the homes for much longer than the heads of other homes. Having vested personal and financial interests, it seemed to me they exerted greater control over what happened in the home at every level. In all small homes the head of home was likely to be the home owner and therefore, not only was there the potential for death and dying to be managed and experienced differently in these homes, but also the experience was more likely to be mediated through the head of home. My expectation, partly borne out by my impressions at the interview stage of the commissioned study, was that the home owner was likely to be a comparatively more influential figure as the head of home than the non-owner manager of a large home.

### *Medium homes*

The way that the medium homes coped with so many residents in shared spaces was also of interest to me. Poplar Court was a purpose-built and spacious home in which movement was a key observable feature; while Church House was a private house converted into a home and residents were cramped into small communal spaces.

### *Large homes*

At the other end of the spectrum, the owners of large homes such as St. Mary's House with 70 residents, Autumn Lodge with 40 and Regis Nursing Home with 35, employed managers to run the home. The impression that I gained from talking to them at interview was that they were less familiar with each resident than the heads of smaller homes. I thought that it was important to explore any lack of familiarity especially if the home was constructed as a domestic 'home' for residents. In an attempt to reduce its institutionalised aspect and to make the homes more 'homely', the larger homes were divided into smaller units. For example, in Autumn Lodge the residents were separated into three distinct units, all of which had its own regular staff group,

separate dining areas and separate lounge. St Mary's House was much larger and was arranged on three floors.

### **3.7.3 Layout**

Size has another dimension beyond that of resident capacity. The home's corresponding spaciousness and layout had the potential to contribute to the way that death and dying was managed. For example, the possibility of death being concealed was affected by the arrangement of space in the home. In those homes which were divided into units, it is more likely that the residents who belonged to the same unit as the resident who died would be aware of the occurrence of a death in the home than those in other units in the same home. It was also more likely that the way that space was managed would vary according to the size of the home and would affect the movement that took place around the home. For example, at interview in one of the homes not included in the field work, the head of home told me about the way in which the design of the home made it more difficult for home staff to conceal the removal of a corpse from the home. One of the striking features of many homes was the way in which in the public spaces the seating was arranged around the walls of the room so that residents were constantly visible to the staff.

The position of the bedrooms and their accessibility also affected the ease with which dying residents could be cared for and the ease of access for other residents in the home who might want to visit. In some of the homes the bedrooms were a long way from the public spaces of the home; while in others they were more centrally located. This would affect the visibility of the activity around the bedroom of a dying resident.



### **3.7.4 Location**

Locality seemed to impact more particularly on the support that was available to homes, the staff who were available to work in them, the length of time that staff were likely to stay and the ability of any family and friends to be able to visit residents. The experience of living in a home at the end of life was one that was partly shaped by the community that surrounded the home and the extent to which the home was part of that community (Komaromy *et al.*, 1999). This would include the extent to which people who lived locally visited the home as volunteer workers, as was the case in St. Mary's House and Church House.

## **3.8 Gatekeepers**

I negotiated access to each of the homes through the head of home as the person with the power to grant access and who served as the gatekeeper to that home. In the commissioned study, I had established that the head of home was the person with whom I would be required to negotiate access to all homes except for local authority ones. In this latter case the formal route was laid down in documentation provided by social services and I sought formal permission from the Association of Directors of Social Services Research Committee, after which I was told to negotiate individual access with each home manager.

In the first instance, I wrote to the head of home, laying out the details of the needs of the commissioned study. I followed this letter with a telephone call to arrange a period of participant observation in each of the homes for the commissioned study and my own fieldwork that would be coterminous. For my thesis observations I would be taking much more detailed notes but this would not affect the time I planned to spend in each home. Initially, I tried to negotiate access during December at a time when the statistics from Stage 1 of the commissioned study showed the death rate to be at its highest. I spoke to heads of homes in the West Midlands, this

being the region in which I lived, to try to arrange my first period of participant observation but they all resisted my being present during the Christmas period. This was a time when the homes were very busy with festive preparations. In all of these four telephone conversations, the heads of home were keen to explain that it was not a good time for me to research death and dying. I also realised that by being in one of the homes during Christmas festivities I might gain an 'untypical' view of that home. I wanted to be able to capture the routines of the homes and to be able to make some comparisons between them and it seemed that I would be involved in the home life at a time that was not representative of the rest of the year. I therefore arranged for my first period of participant observation to take place in January 1996.

As stated earlier, I wanted to keep the exact period of entry into the home as fluid as possible so that if someone was dying at a time when I was due to leave that home and move on to the next I would be able to stay longer. I therefore gained an initial agreement with heads of home to the principle of my being present in the home for a period of two to four weeks of participant observation and an approximate length of time that I would be in the home doing participant observation. I visited each home in turn to discuss the detail of what being a participant observer meant and address any concerns that they might have. In six of the eight homes, the heads expressed concern about how I would approach the subject of death and dying. I explained that I would initially talk to residents about their life in the home, that I might ask if he or she expected to live this long, and only discuss issues related to death and dying if the resident raised the subject. Despite my own concerns about the complexity of what I was doing, the issue of being there, as a researcher on a commissioned project and collecting data for my PhD did not raise any concerns with any of the heads of homes.

There were varying degrees of openness in the homes. At one extreme, Sister Margaret, the head of St. Mary's House and a Catholic nun, was very interested in the

commissioned project and my thesis and told me that I could have access to the home at all times. She told me that there was no need to report to anyone to tell them that I was there, unless I wanted them to provide me with a meal. I was also able to return to the home to talk to the staff and residents and this is what I did.

Conversely, the heads of other homes were more concerned to control the degree of access by expecting me to tell them when I would be in the home and for how long at each visit and overall. For example, Rugby Nursing Home, a large private nursing home, was run by a woman, who held the title of 'matron' and who had many years of nursing experience. When I visited her to discuss the details of my role as participant observer in the home, she was very concerned to know how I would approach residents and handle what she saw as a very difficult subject for residents to discuss. She seemed to be reassured when I told her that I would approach residents very carefully and would let them lead the discussion and thus only take it as far as they wanted to go.

Because I wanted to build up retrospective accounts of some deaths in the homes, I also negotiated access to people who were external to the home and whose views on death and dying would provide useful information and different perspectives on death and dying. This included, for example, the written accounts of death, the recollections of the residents in the home, the accounts from staff involved and the relatives' accounts. I sought access to GPs and community nurses directly. This was done after negotiating access to the home and during the fieldwork. If I was going to develop retrospective accounts of deaths, then it was impossible to know in advance which deaths I should consider. The head of home served as gatekeeper to the relatives of deceased residents and to the community nurses.

### **3.8.1 Reflections on my role of participant observer**

Of course it is important that gatekeepers should protect the interests of those whom they perceive to be 'in their charge'. However, on reflection, this protection was based on an assumption that death would be upsetting to all of the residents and was a subject that needed to be approached with some caution. Treating the subject of death as a sensitive subject and in need of careful management is part of the whole production of death as special, and this belief is one that, as a researcher, I set out to unpack.

### **3.8.2 Negotiating access**

In this section I discuss what I set out to negotiate with the heads of homes in my preliminary visit. I also discuss how gaining access is not a one-off event but is a process that evolved in each of the homes and during the fieldwork. I had to negotiate two types of access. The first was for the commissioned study and the second for my thesis fieldwork. I was clear that I wanted to try to be present in the homes when someone was dying and at the time of death. In preparation for this I devised a plan whereby I would locate myself in all four homes in one region so that I could effectively be on call when residents were thought to be dying. I intended to try to gain agreement with each head of home that, if a resident was thought to be dying, I could return to the home during the six-month period I had set aside for the field work in that region. The reality was different and that is discussed later in the section on leaving the field.

In all homes, it was the head of home who gave consent for access. There were varying degrees of discussion with the staff about my presence in the home and in five of the eight homes the head of home told me that access was dependent on the staff's agreement to my presence. However, the head of home did not consult with the residents prior to my period of study in any of the homes. Many of the heads

of homes who agreed to my doing participant observation in their home voiced a concern about how I would introduce myself to the residents. With the exception of one home, there was an assumption that I would not disclose the purpose of the study to the residents. In death and dying research gaining consent presents difficult issues of disclosure and, therefore, telling residents that I was researching death and dying could indicate to residents that they were thought to be dying. Mainly, I introduced myself as someone who was looking at all aspects of the quality of life in care homes.

I was aware from the Stage 2 interviews with the heads of homes in the commissioned study that staff shortages were a serious concern for most of the homes. This meant that my freedom to be able to observe the key events surrounding death and dying could have been compromised by being given a set workload, as if I was a member of staff. Therefore, it was important to the success of the fieldwork that I should be able to agree clearly what tasks I was prepared to do and what I could be expected to do in each home. Apart from my need to be free to observe significant events in the home, particularly at the time of dying and death, I also had concerns about being accountable for any tasks that I performed that were in the category of 'nursing care'.

Given all of this, I decided that the best status that I could negotiate would be one equivalent to that of a voluntary worker in the home. When I talked to home managers, we agreed that in all of the eight homes I would be able to talk to residents, staff and any visitors, with some conditions set by the head of home, which related to notifying them in advance about the timing of my visits and the overall length of my stay and help at whatever level the head of home agreed was appropriate up to that of the status of a voluntary worker. In other words, I was not depended upon as a member of the staff team and, even though I had much nursing experience, would not be expected to participate in 'nursing' tasks.

In practice, the level of involvement that I was able to negotiate varied between homes. In some homes the head of home was willing for me to work alongside a care worker and to help residents with basic daily care. This included, for example, getting residents out of bed and washed before taking them to the dayroom or dining room. When this happened I had the opportunity to see things from the perspective of that particular care worker through the experience of the physicality of the task, from hearing the conversations that took place between the care worker and the resident and the account that might be given to me of what was happening.

I also wanted to be present in the home at different times of the day so that I could meet the staff on each shift and observe the different routines that took place in the mornings, afternoons, evenings and at night as well as shift changes. The periods of time that I negotiated and spent in each home also varied. In general, in the smaller homes I spent less time than in the larger ones. There are several reasons for this. First, the negotiation of involvement in smaller homes meant that I was more conspicuous. In Peacehaven, Pat Walker, the head of home, wanted to be present when I was there and it proved difficult for me to arrange to be there at other times. She also wanted to ask permission of the staff who worked on the evening shift and the night shift for me to be present in the home. Second, I found that in the smaller homes I did not need to spend as long in collecting data, since the routines and variation in them was not as great as in the larger homes. Third, the death rate was lower in the smaller homes and it would not take me as long to collect accounts of death and dying. It followed that those homes that were separated into units were effectively several small homes and would need longer periods of participant observation.

### 3.8.3 Ethical considerations

As a branch of moral principles and virtues Ethics is far from straightforward. Barnes (1979) suggests that ethical decisions arise from the need to choose one course of action in terms of what is morally right and wrong. But this is not straightforward and, as Singer (1993) point out, within ethics itself, even though there should still be standards of consistency and relevance, there is no objective truth. Feminist researchers have made persuasive arguments for research to be shared by those involved, in order to deconstruct the power divide between researcher and researched. Many researchers such as Lawton (2002), regardless of their degree of openness about the research process, admit to feelings of betrayal as they place their own interpretation on the data. Research presents grey ethical areas in which researchers wrestle with their conscience. I was aware that I had a responsibility to behave in an ethical manner and also avoid value judgements about the setting in order to record what was happening as accurately as possible. I knew in advance that I was not prepared to tolerate cruelty and suffering, if I could intervene to stop this happening. In other words, I had worked out that there was a trade off between the quality of the data I collected and the experience of dying residents.

Ethical committees usually provide written guidelines, which frame individual cases. Certainly the British Sociological Association produces research guidelines that it is assumed sociological researchers will follow. However, I argue that, despite these guidelines, there remain contradictions and tensions inherent in the practice of ethics. First of all, researchers have to decide if ends justify means or if the means are ends in themselves. This deontological and consequentialist divide is highlighted within all types of research and is a significant feature of the debates around the purpose and value of research, which in turn, is founded on beliefs about the status of reality. Negotiating access with those heads of homes who wanted to protect 'their' residents while at the same time making public their own concerns about death and dying,

raised fundamental questions; in particular, the need for the protection of older people and the extent to which protection and advocacy could compromise individual rights. Such ethical dilemmas feed into a broader debate about the role of ethics committees in a care sector that is largely independent and fragmented. Without overcomplicating this debate, I want to highlight that ethics is not straightforward and that ethical considerations are not one-off features of research, negotiated at the point of access to the field but part of a continuous process of negotiation.

During the fieldwork there were two occasions on which I intervened for ethical reasons. One was when a resident in Regis Home, called Alice and described in Chapter 1, was suffering intolerable pain and matron told me that she would inform the GP in a few days' time, which I considered to be unreasonable. On the second occasion, and in the same home, I insisted that care staff invited two residents who were close friends of Alice to say goodbye to her before she died.

## **3.9 Participant observation**

In this section I discuss the role of the participant observer, the data that I collected and reflect on the relationship between my role and the data.

### **3.9.1 Being there and being a participant observer**

On my first day in each of the homes I arranged to talk to the head of home to discuss the specific detail of what I would do in the home. In all of the homes the head of home showed me around and introduced me to the staff who were on duty. I explained who I was to everyone to whom I spoke and I found that this explanation evolved and varied over time and between homes and individuals and met with different degrees of comprehension. I soon realised that the process of negotiation was ongoing.



Researchers are not common visitors to homes for older people and the process of research was something with which most heads of homes, staff and residents were unfamiliar. Mrs Stoney, the head of Beech House, treated me more like an important guest and often enquired after my comfort and offered me meals and drinks. Members of home-care staff were often keen to talk to me and give me their views about what was happening, explain issues that related to the constraints under which they worked and provide accounts of deaths in the home and their role in these. Some disclosed to me their own needs related to loss and bereavement. The various degrees of interest of these staff members contrast with those who seemed less interested and even suspicious of me. I realised that the interpretation of what I was doing affected the degree of enthusiasm with which I was received.

I went to the staff room at staff breaks and mealtimes and listened to their conversations; sometimes asking questions for clarification. It was here that I heard more personal views about what happened when a resident was thought to be dying. This included staff views on that particular resident's course and duration of illness and predictions about his or her death.

By contrast, residents in all of the homes appeared to be happy to talk to me, and occasionally I arranged a mutually convenient time for someone to talk to me privately. Mostly, I approached residents and introduced myself, but some heads of home introduced me to the residents. In Seaview house and Peacehaven the heads of home wanted to ask permission for me to talk to those particular residents who stayed in their rooms. When this was the case, I was given a time when each resident was willing to talk to me. For example, two residents had been bereaved by the loss of another resident with whom each had become a close friend and it seemed appropriate to put this onto the same level as the interviews with the relatives of deceased residents and I tape-recorded the two interviews. This also enabled me to use their own words. One of these residents, Tom at Beech House, wanted to see a

copy of the transcript and I sent him one, inviting him to comment, but he did not do so.

The task of helping with serving meals and with feeding was my most common form of involvement. Indeed in all of the homes in the study, there were residents who were unable to feed themselves. In the smaller homes, the heads of home did not want me to participate in personal care tasks. In all of the homes I was able to be present at different times of the day and night.

### **3.9.2 The people I spoke to**

As described above, during my fieldwork I spoke to residents, staff members, and also arranged through the head of home to talk to any visiting community nurses and GPs. The accounts of general practitioners (GPs), community nurses involved in the dying care and also the relatives of deceased residents provided important aspects of these deaths. The main purpose of these interviews was to build up retrospective accounts of recent deaths in the home. The interviews with relatives of deceased residents, community nurses and GPs were tape-recorded and transcribed. Because I wanted to be free to listen actively to what they were saying and in the case of the relatives of deceased residents it was particularly important that I should be a sympathetic listener since they were likely to be grieving.

Apart from those GPs who agreed to talk to me on visits to the home, it proved to be difficult to get access to many of the GPs and I had to try hard to get an appointment with them through the practice manager. The constant message I received was that they were too busy to talk to me. On the occasions that I gained access and arranged for an interview, I was asked several times for payment for their time. In the event, although I was offered just twenty minutes of their time, those who talked to me did so for much longer and seemed to be pleased to be able to offer their opinion on the way that death and dying was managed. GPs provide the main

source of support to all types of homes and served as gatekeepers to resources when residents were ill and thought to be dying. More significantly for this thesis, they diagnosed when a resident was dying and, through varying degrees of negotiation with the head of home, whether or not the home staff could manage the resident's terminal care. If not, they arranged for residents to be transferred to another home or hospital. It is also the case that GPs made key decisions about whether or not a resident could be treated when they were ill; the nature of that treatment and what and where it should take place.

### **3.9.3 The process of participant observation**

Participant observation as a research process involves the types of openness and adjustments that I discussed in, Section 3.3. The nature of the reality of being in the field was that, wherever possible, I would record my field notes as close to the period of observation as possible. This meant that I was also recording my reflections and asking myself what further data I might have collected. There were times when I regretted not following up on comments that staff or residents made and which I found difficult to ask about or for which I assumed a shared understanding.

While it is the case that during the time that I was in the field I was also recording an account of being in the field, and reshaping and framing my data this led me to consider the future data that I needed to collect. This process of developing my focus on areas, and also the development of emergent patterns from the data, were essential features of my data analysis. In Section 3.11 I discuss this further.

In some ways I narrowed down the focus into that which was directly relevant to the thesis. This in turn, was much wider than the data that were needed for the commissioned study, so that the two tasks were not in conflict. I was entering eight different homes and my focus was on death and dying, therefore, on one level I was able to make comparisons between homes. However, the aspects that began to

emerge from the data needed to be 'captured' so that I could carry them forward to the next home. I had talked through the potential difficulties that might be involved in this type of transient fieldwork with my supervisors and agreed that I would conduct my first set of observations in the largest of the homes, St. Mary's House, and spend as much time there as possible, before discussing the data that I had collected and being clear about the feasibility of what I was doing. The freedom of access that this first home offered me and the opportunity to stay there overnight, as well as being present when one of the residents was thought to be 'dying', provided a diverse range of data and ideas for deepening my thinking about what I might want to focus on in other homes.

### **3.9.4 Written records**

Accounts of death and dying were contained in some of the written records in homes. In particular, the notes that nurses and carers made during the dying period that included the care that they gave and any information that was considered to be important, such as GP and family visits and the stages of deterioration. In seven of the eight homes these accounts were kept in a report book. I copied by hand these written accounts about death and dying. Many of the accounts were very brief. It was important to this thesis that I captured the ways in which the period of 'dying' was marked, as I will show, and I argue that this also implies what was considered to be worthy of recording.

### **3.9.5 My fieldnotes and when these were recorded**

As noted in Section 3.3, my aim was to gather and record as much detail as possible. I was aware that field notes need to be organised into some broad categories from the beginning (Hammersley and Atkinson, 1995) and I used headings and different places in my notebook for different types of data. While there had to be some way of being

able to retrieve data and to recognise the status of it, it was important that it was stored in a way that did not predetermine my analysis. My field notes included descriptions of what was taking place in the home, precise notes on what was said in quotation marks, summaries of what people said and my reflections on what was taking place. I tried to be careful to record descriptions rather than impressions of what was taking place. Silverman (1995) calls these 'flat, unadorned descriptions'. As the fieldwork progressed, and as discussed in Section 3.9.3, I was able to develop the following broad categories, such as 'what happened when someone was thought to be 'dying' and how and by whom that decision made. In particular, after the first period of observation in St. Mary's House, I spent a lot of time reading the data, considering how to record my notes more effectively and what I wanted to make comparisons with more precisely. For example, I realised that I needed to be able to answer questions such as, what happened when someone was 'dying' and what made this different from 'living'? Atkinson (1990) argues that a conceptual grid can provide a useful tool on which to record data, but there is a danger that having a grid can become a constraint, and I was careful to allow for events that might fall outside of broad categories, but which might be relevant.

As well as recording and reading my daily field notes, before the end of the day I also listened to any recorded interview which I made that day, partly, to ensure that the interview had been successfully recorded, and if it had not, to make detailed notes on what had been said, and also, to remind me about what had been said, so that I could carry the data forward into the field and be aware of any associations that seemed to be important. This was especially important as I built up the retrospective accounts of death and, for example, it provided me with a guide of what I might want to explore further with other people involved in specific deaths.

In many of the homes I was able to find a quiet place in which to record the details of what was taking place. I made an effort to explain to staff when I was doing

this, that I needed to be able to take notes on what I had seen and heard. Of course, it wasn't possible to record all of my field notes while I was in the home and I spent several hours each evening in completing them. It was important that I completed field notes at the end of each day so that I could record what was taking place as accurately as possible.

### **3.10 Leaving the field**

I tried to leave the field in a way that would allow me to return to the home in the event of someone dying. However, I only returned to two of the homes, Regis Home and St. Mary's House. In Regis Home I had just ended the planned period of study when the head of home contacted me to inform me that Alice was thought to be 'dying'. After being present for the death of Alice I arranged to return a month later in order to talk to the staff and residents about the impact of her death upon them all. In St. Mary's House, the head of home, Sister Margaret was happy for me to keep in regular contact and I returned to this home following an invitation from her, when one of the residents was thought to be dying. This time I stayed for one week and the resident who was thought to be dying recovered.

While most heads of home wanted feedback on what I was 'finding out' some wanted reassurance that I found them to be caring well for their residents. In two of the homes, Regis Home and Victoria Care Home, it was important to the heads of home that I was clear about the outcome of my research. In Regis Nursing Home matron wanted me to provide her with more formal feedback and arranged a time for me to do this at the end of the study. Most of the homes were keen to receive a copy of the commissioned report and I sent them all an executive summary.

### **3.11 Analysis of data**

Brewer (2000) argues that, at its simplest, analysis is a way of bringing order to the data. I have already described how part of my analysis took place during the fieldwork and this was an ongoing process, rather than a discrete stage of the research process. I found that I was reflecting on the data in ways that meant certain parts were distilled into some form of coherence. Brewer describes these two types of analysis, 'in the field' and 'after the fieldwork' as part of the management of data and the capturing of social meaning. By analysing data while I was in the field I was able to assess and sort the data, but it was important that I should be able to look at the data in a fresh way and return to my original questions about what was taking place when a resident was thought to be 'dying' and when he or she died. The second form of analysis, 'out of the field' (Brewer, 2000) was a much more detailed exploration and involved breaking down data into codes. This meant that I coded the data and then further coded each part into sub-codes. For example, any reference to 'dying' was coded as 'dying' and then further coded into 'types of dying'. I also made several copies of my field notes, transcripts and copied written records so that they could fit into several categories, which allowed for the coded data to be considered in different categories. I then looked for patterns between the codes so that the data could be classified into broader categories. For example, certain codes related to each other in ways that comprised a category, such as 'compensations for 'dying'. I then built up these categories into broader themes with coded data sometimes fitting into more than one theme. Finally, I was left with three main themes, or metacategories: 'bodies', 'time' and 'space'. For example, at its most general bodies could be coded as – 'living', 'dying', 'dead' being moved and handled through 'space' that was both physical and temporal. This allowed me to capture all of my coded data and left me with an image that represented a broad picture of my experience of being in the field

that would allow me to discuss the way that death and dying was produced in homes for older people.

### **3.12 Summary of key points and conclusion**

In this chapter I have written an account of the methodology and the ideas that have influenced my thinking about the best ways to capture the type of data that I needed to answer the questions that this thesis explores. This included a debate about the nature of reality and how I located myself in that terrain. At its simplest, I have argued that by being present in homes and witnessing what happened when someone was diagnosed as 'dying' and at the time of death, I could capture a reality separate from me as the researcher. I have also argued that my presence in the field was part of the context of that reality, but that this had a greater impact on some levels of context than on others. For example, in individual encounters with staff and residents my presence was more likely to produce events that might not have occurred without me. Conversely, it remained the case that any involvement that I had was negotiated through the head of home, and furthermore, that the routines and social context of homes were less likely to be affected by my presence. In other words, I argue that, while it was almost certainly the case that I would affect the microcosm of care home life, I could not significantly change the structural context of living and the dominant discourses that were part of the way that death and dying were constructed and produced.

I have discussed ways in which the special nature of sensitive research requires a particular approach that takes into account the vulnerabilities associated with the way that death and dying is constructed. I have further argued that my own need for extra support enabled me better to manage this vulnerable area and locate myself more objectively in this field of research. These methodological considerations



have informed the methods section in which I told the story of how I collected the data, and the experience of entering and leaving the field.

Finally, the analysis offers one interpretation of the ways in which death and dying was produced in these settings. I am conscious of the choices that I had to make in selecting which data to use to provide this interpretation and the way that this focus left out other peripheral aspects of my observations in the homes I studied. Here I acknowledge that the limitations of this thesis meant that I could not include everything. However, because the study involved several homes, and because the focus was always on death and dying, I am satisfied that what I have provided represents a central, focused and accurate account of death and dying in care homes for older people.

.

## **CHAPTER 4**

### **'Living' in care homes for older people**

#### **4.1 Introduction**

In my consideration of what it meant to be 'dying' in a care home, I realised that it was essential that I show how the status of 'living' was achieved. This chapter serves two main functions. First, I set up how the concept of 'living' was produced as a preparation for my consideration of 'dying', which follows in Chapter 5. Second, related to this but distinct from it, I argue that when 'living' residents were suffering from multiple and chronic conditions, there were significant consequences that followed the assignment of such a resident to a 'living' category. The example of Alice in Chapter 1, highlighted the way that her bodily pain and distress that erupted through the apparent calmness of 'living' was not adequately acknowledged, nor was it addressed. I argue that this calm was maintained through normal sounds of talking and not showing great distress. Furthermore, in this chapter I explore how the gap between the capacities of 'living' and 'dying' was sustained so that its ambiguity was minimised. However, despite attempts to separate 'living' and 'dying' residents, it is important to note that some residents did not achieve either 'living' or 'dying' status and instead occupied a liminal space between 'living' and 'dying'. I introduce one such 'liminal' resident in this chapter called Laura, who was thought at one point to be 'dying' but survived without re-entering the public spaces of 'living' territory. Therefore, while the status of 'living' in residents who could be considered to occupy a 'living/dying' status and who might fluctuate between these two

states is partly arbitrary, there were significant premiums on getting both 'living' and 'dying' right.

In the Chapter 2, I argued that older people are marginalised in western societies and that those deemed to be incapable of independent living, are sequestered in care homes. According to Goffman (1968), the social arrangements that incarcerate people under one roof and, according to one rational plan, regulate all spheres of institutional life, which he called 'total institutions'. One result of attempting to reduce the dependency of institutional life (Booth, 1985; Townsend, 1962) is a focus on 'living' and rehabilitation. These institutions of care homes, which have received much attention, have incorporated attempts, to guard against the dangers of institutionalisation. I would argue that, despite these attempts, care homes for older people still fit into the category of 'total institutions'. Furthermore, I argue that, as a form of institutional care, the way in which residents were spatially positioned at regular times, within these institutions, acted as a powerful form of control over residents' ageing bodies. However, within this broad frame and ordering of the routines of everyday life there are clear distinctions to be made. In Chapter 2, I highlighted the way in which Willcocks et al (1987) warned against the dangers of over determining structural dependency. Having made that qualification, I describe below some of the detail of 'rehabilitation' and how this was produced through the routines and practices of homes for older people. I argue that for most residents in a care home, in which death was the ultimate outcome, rehabilitation was a routine through which a performance of 'living' was *produced*. Also, rather than being the opposite of institutionalised 'life', rehabilitation has become a form of institutionalised 'living'. My data showed that this production of 'living' took place through routines and practices, which included residents being got out of bed, washed, dressed and then taken to, or encouraged to share the public spaces of the home with other residents in which they took part in further routine activities of 'living', such as eating and drinking.

I will highlight general shared features of the eight homes, which contributed to 'living' and in which I collected data for this thesis. For example, care staff washed, dressed and got most of the residents out of bed in the morning and took these residents to either the dining room or the lounge. This emphasis on the bodily care of residents, and getting them into the communal areas of the home, was made possible by the way in which the staff rota was organised. In common with many care homes for older people (Sidell and Komaromy, 2003), the highest ratio of staff to residents was in the morning, so that, while the time and length of this shift varied between homes, heads of homes consistently arranged the staff rota in this way. There were also similar patterns in the way that the staff routines were organised and when care staff performed certain tasks.

However, I argue that the production of 'living' through routines and practices was not straightforward. While my data revealed that the routines and practices associated with 'living' existed in all eight homes in which I conducted field work, residents occupied various stages of 'living', so that for some residents, 'living' was easier to achieve than for those far less capable of conforming to this category. This is despite the elasticity with which the qualities that comprised 'living' were interpreted.

In my discussion of methods in Chapter 3, I provided a picture of these homes through characteristics such as size, type and location. This served to contextualise the settings and describe the institutional features that framed the care that took place. The data that I collected were extensive and I discussed the way that I analysed this data to produce categories that comprised the detail of the features of 'living', 'dying' and death. The data presented here, are mainly in the form of vignettes that illustrate a more comprehensive picture of what I observed in my fieldwork. I discuss the use of the vignettes below.

## 4.2 The use of vignettes as data

These vignettes illustrate the routines and practices of 'living' and highlight specific qualities of 'living'. I describe each home setting and discuss particular home features in order to develop a more coherent picture of 'living' in a care home. Against this background of highly structured and repetitively organised days, I present detailed examples of 'living' in care homes. Each vignette demonstrates the particular features of 'living' which contributed to the way that this was produced and its prominence in home life.

The first vignette provides an account of Emily, who was the only mobile resident of Poplar Court, a large nursing home in the West Midlands of England (see Table 3.1). This view of Emily's life in Poplar Court contrasted with the other immobile residents who spent their days sitting in the public spaces of the home. The second vignette involved a typical day in another large nursing home in a town in the West Midlands, called Regis House. The vignette focuses on two residents, Maude, who was a wheelchair user and her participation in an activities' session, and Millie, a confused woman who was able to move independently, and who constantly wandered around the home. The vignette contrasts two ways in which different residents in the same home were constructed as 'living'. The third, and final, vignette provides an account of Tom and Grace, who were residents in a small residential home, called Seaview House. Tom was very active and went out of the home unescorted on a daily basis, compared with Grace, who had been expected to die the previous year and who had survived. Tom provided his own account of what it meant to be 'living' in Seaview House.

All three vignettes contrast types of 'living' both within and between the homes, while at the same time they highlight the continuities of the way that 'living' in institutional settings was produced. I would argue that producing the status of 'living' as a form of rehabilitation, also served the function of separating 'living' from 'dying' residents. For example, as stated earlier, in all homes in which I collected data for this thesis, the

staff shared similar routines that structured the events of daily life. These included performing certain tasks at set times of the day. Many home routines were structured around when care staff began and ended their shifts and were organised according to the way that the work of the home was prioritised by the head of home.

For example, breakfast time in study homes was flexible so that residents could take breakfast any time between early morning and just before lunch. Other meal times were less flexible because lunch and supper were often cooked meals that would 'spoil' if left or reheated. A senior staff member administered prescribed medication to certain residents before meals and at bedtime. Care staff took incontinent residents to the toilet at regular intervals, before, and after meals. Any entertainment or rehabilitative activity that took place happened in the afternoon and, occasionally, in the evening. Family and friends were more likely to visit in the afternoon or early evening and especially at weekends. All residents were encouraged to go to bed or to their room by ten o'clock. In all eight homes in which I did participant observation, care staff verbally handed over 'relevant' information about residents from one shift to the next, called 'the report'. This verbal report was given up to three times a day.

The following vignettes taken from three homes comprise a mixture of direct quotes from fieldnotes and summaries of my observations and conversation. I provide additional detail about each home that expands upon the more general information provided in the methods section of Chapter 3.

### **4.3 Vignette 1: 'Living' in Poplar Court**

Vignette 1 highlights features of 'living' in a home where most of the residents had high levels of need for physical care. I use examples from fieldnotes to illustrate the way that the bodies of residents were constantly managed to keep them clean and fed. The residents of Poplar Court were moved around the home and placed in public spaces of the sitting and dining rooms. The design of the home makes the public spaces central to the

home and the practice of policies of the home helped to sustain the residents physical bodies as the main focus on 'living'.

#### **4.3.1 Background to Poplar Court**

Poplar Court, situated in the urban part of the West Midlands, was a purpose-built 24-bedded home whose residents had formerly lived in a long-stay NHS hospital ward. When the hospital continuing care ward closed, it was reconstituted through a voluntary trust fund and NHS contributions as a nursing home. The staff, who previously worked on the NHS ward, were all re-employed in the home.

Poplar Court was designed as two rectangular wings adjacent to each other, so that the main body of the home was formed as a square. This left two wings that housed the bedroom accommodation and utility rooms. The body of the home was where the communal areas of two sitting rooms and one dining room were situated.

Poplar Court retained many of the practices of the hospital ward and this made it distinctive from other homes in this thesis. The staff wore a hospital uniform whose colour denoted their status. The tradition of keeping written records of the hospital ward patients, as well as medical notes, meant that a senior staff member wrote a report of each resident in a Kardex, which formed the basis of the handover report for each of the three shifts; early, late and night time. There were many more written records in evidence than in the other homes and staff were more likely to record routine observations of pulse, temperature and blood pressure. The home also employed a GP who visited every day and the senior member of staff decided which residents he needed to see. This resembled a hospital ward round. The GP also reviewed the care of each resident at least once a month, so that, regardless of the need to be seen by the GP, none of the residents went for longer than one month without being medically examined.

In Poplar Court there was a total no-lifting policy in operation which meant that staff were expected to use hoist and other equipment to lift residents. The result of this

was that there was a lot of lifting machinery in use in the corridors of the home as residents were conveyed to various parts; from the bedroom to the bathroom, and then, to the main lounge or dining area.

Each morning, immediately after breakfast, the staff washed and dressed all of the residents and then wheeled them from their bedroom into the sitting room. The contrast between the movement of the staff as they wheeled residents into the room, and the stillness of the increasing collection of seated residents, was striking. The most common scene that I witnessed was that of residents sitting around the walls of the lounge with the television playing loudly in the background, and serving as a barrier to any conversation; staff explained to me this was because many of the residents had a hearing impairment. Light entertainment programmes would most often be shown on the TV and a popular programme was the daytime chat show. The noises in the home were comprised of several types of noise: staff shouted to each other and at residents in loud voices; the television dominated the lounge with the volume turned up high and there was the constant noise of pans and cooking from the kitchen as food was being prepared. A few residents, but by no means all, looked at the TV. Mostly staff chose the TV channel, although occasionally, I witnessed some residents being consulted.

The routines of the day were organised around the mealtimes. For example, after the lunch was served, the exodus to various parts of the home began. Some of the residents were taken to the toilet and the staff called this activity 'toileting'. Other residents went to their room for an afternoon rest and lay on the top of a made-up bed with a blanket covering them. The remainder were taken back into the lounge area. In the afternoon at 3 o'clock the residents were returned to the lounge from their rooms for the afternoon recreation period. A variety of entertainment was provided. For example, one day a rock singer sang and played a guitar. In common with the choice of TV programmes, the rock music and singing seemed to jar in its 'out of time' and 'out of place' nature.



At 5 pm residents were given their tea. Again this involved a migration to the dining area. Special and different food was served, again according to each resident's eating status. After tea, residents were taken back to bed, which took over two hours. Throughout all of these tasks, the staff wheeled equipment, commodes, hoists, wheelchairs, to and fro sometimes containing a resident and sometimes not.

The following vignette is taken from fieldnotes during one day of participant observation in Poplar Court and provides an illustration of Emily who was different from the majority of residents in Poplar Court because she was able to walk independently and provided her own personal care. It is this contrast that throws the plight of the severely disabled and dependent residents into sharp relief and provides clues about how 'living' was constructed and produced in Poplar Court.

**4.3.2     The 'life' of Emily at Poplar Court**

The nurse in charge of the morning shift with whom I had been making beds suggested that I might want to talk to Emily. I introduced myself to Emily and together we made our way from her bedroom along the corridor, through the main resident's lounge to a smaller one. Emily was the only resident who could walk unaided – although it seemed to me to be quite a struggle and she walked very slowly. We made our way, slowly, to a small sitting room walking past the dining room on the right and the main and open lounge further along on the left. This lounge was small with just six chairs in it and a television in the corner. It was enclosed on two sides by glass walls and the corridor and main lounge were clearly visible. There was another resident in the small sitting room and she and Emily exchanged a greeting. Emily introduced me to her housemate, Sophie, as if I was her guest. She then invited me to sit beside her and away from Sophie.

**Fieldnotes: Being mobile**

*Oh the most important thing – my legs are everything to me. I'll show you what I mean.* Emily dug into her handbag and after some searching

showed me a letter. It was written by another resident who had been discharged home. Emily told me that this was her inspiration. I read the letter that she offered and felt moved by it. Emily was clearly impressed by her letter. She explained to me that this resident was not able to look after herself when she came into Poplar Court, but she was so determined to go home again that she 'got herself walking'. Emily also told me that her last words to her when she said goodbye were, *You can do it. Look at me, I did it!* Emily was determined to go home and I asked her about life in Poplar Court. She told me that it was not so bad and that it was one of the best, but *it isn't home*.

This was a comment that I heard several times from other residents. I pursued the topic of 'living' in the home and asked why it was 'not home'. Emily explained to me that there wasn't anyone to talk to. I looked across at Sophie anxiously and she was sitting close to the television watching a chat show. She did not appear to have heard this. Emily saw me look at Sophie and shook her head and whispered, *She won't get out of here, it's her heart*. After a deep sigh, Emily told me, *they all die in here*. (She nodded at the residents in the main lounge on the other side of the glass door to this smaller lounge) *Look at them, they're waiting to die. They don't even know what's going on*. Again I noted her compensation following a harsh-sounding comment.

At 11 am a staff member wheeled the tea trolley into the lounge and offered Emily a drink. *Here's your tea, Emily!* she shouted above the noise of the television. *Thanks, dear*, said Emily, as she took the cup. There was a biscuit already placed in the saucer. Emily told me that when she had drunk this she would go for another walk. She explained, *I keep myself walking*. We both understood the significance of this remark from what she told me about leaving the home. I said good bye to Emily and returned to the main lounge. One of the visitors said 'hello' to me and

I reciprocated the greeting. *Are you visiting?* he asked. I was aware that shouting a response across the lounge and above the sound of the television seemed to be too insensitive. I walked across to the visitor, but all of the chairs were close together and he was sitting in front of his mother – there was nowhere for me to sit and I leant over to answer him. I realised that I had created an awkward ‘position’ for myself. *I am working here as a researcher. I am looking at the quality of life here in the home.* He didn’t seem to know what to say next and said, *Oh.* I asked him how often he visited the home. *Every day, I come to see my mum here.* He stroked her hand and got no response. His mother was asleep and almost lying down in a reclining armchair. Her hair was combed straight and she had a clip in it worn in the style of a child. She wore a floral dress and a cardigan. I asked him his mother’s name. *Mrs. Althrop.* He replied. *How long has she been here?* he told me just a few weeks. I wondered if we were sharing the same thought about how much longer. *They look after her very well. I’ve no complaints.* He volunteered this information. I told him that she looked very well looked after, and he seemed pleased and smiled in response. I moved away and went to the dining room.

### **4.3.3 Managing social death?**

In the scene described above, Emily was comparatively ‘fit’ in a home in which the majority of residents were ‘frail’ (Hockey, 1990). Emily seemed to have set herself apart from the residents in the home and kept her focus on the outside. Despite being what she described as ‘very ill’ on admission, she recovered and no longer identified with the other home residents. It was clear to me that Emily was different from the other residents in that she would soon be able to walk without assistance. From what Emily told me, she

saw her ability to walk unaided as part of her way out of the home. Her evidence for this was based on the fact that most of the other residents were immobile and someone whom she had witnessed as being able to walk was able to return home. For Emily it was possible to 'lose' the need for care and to earn the right to return to her home. I would argue that she was resisting and challenging the one-way and linear progression to death that she had witnessed in the home.

For the care staff of Poplar Court, keeping the residents going was both a physical and emotional task. The physical aspect involved moving the 'living' bodies of residents who could not move themselves into different parts of the home at set times. For example, from the bedroom to the lounge and dining areas, to and from the toilet and then, back to bed. The emotional aspect involved cheering up residents and keeping them occupied with entertainment and therapy.

The TV programmes and the staff conversations about their lives and the sounds from the kitchen were clear representations of the life that existed outside of the home and seemed incongruent. On one level, they did not reflect the reality of what was happening in the home; neither did they seem to have anything to offer residents, since they were mostly chosen by the home staff. On another level, the noise seemed to highlight, through the absence of meaningful conversation, the bodily care that the staff performed by excluding the emotional or social needs of the residents.

One of the striking features of home life was the way in which home staff managed the ageing bodies of residents. In all of the homes in which I made my observations this was the prime pre-occupation of the staff. Any other forms of social care were secondary to the physical care of residents, the care of ageing and failing bodies. In Poplar Court the staff focused almost exclusively on the physical side of caring and ensuring that the residents in their care took on the appearance of 'living' residents.

In Chapter 2, I argued that Sudnow (1967) presents death as both 'natural' and 'social'. But life also has natural/biological and social meanings. For example, food and

drink were mediums through which people could acquire membership to 'living' status; they sustained the 'natural' living body and were cultural symbols of life and 'feeding' residents brought together the biological and symbolic act of 'living'. Those residents with less easily distinguished features of 'living' were presented as performing the tasks of 'living'. It seemed that the physical boundary between the two lounges spatially separated those residents who needed to be observed and clearly were observable and those who did not. The small lounge was afforded to those two home residents whom staff considered were not in need of being observed. It was as if Emily and Sophie had retained some independent status which in turn awarded them a measure of social worth.

The next extract from my fieldnotes describes one typical mealtime in Poplar Court.

#### **Fieldnotes: Lunch at Poplar Court**

The tables were being set for lunch and my offer to help was accepted. At 11.30 the staff began to move the residents into the dining room in wheelchairs to tables, for their lunch at midday, while other residents were helped to their feet and made the slow journey by using a Zimmer frame and some assistance from a staff member. The television set was turned down and the noise of instructions being shouted replaced its sounds. *Come on Mary; put your foot forward, that's it'. No!* shouted a care assistant. *You have to go to the toilet, before your dinner!* The nurse in charge of the shift gave me my instructions. *Can you wheel this one in please and you can feed her.* This one was Daisy, a large woman in a wheelchair and one of only two black women in the home. She did not speak to me and had the lopsided face of someone who had suffered a stroke.

Other residents were wheeled to a table and remained seated in their wheelchairs. All of the 7 residents who needed to be fed were seated

close to each other. The kitchen staff appeared with meals on plates and the staff put 'bibs' on some residents while others had serviettes. I was enlisted to help feed more residents, after I had fed Daisy, who chewed her food a lot and did not seem to want to swallow. I felt anxious that I was slower at feeding than the care assistants who were cramming the food into residents' mouths. I noticed that their residents were willing to be fed. They ate quickly and sat with open mouths waiting for the next mouthful. I realised that I had been allocated three residents who did not want to eat.

(This told me that they were 'unpopular' residents. But what made them so? Is not eating the same as being 'difficult'?)

At last I had fed my charges and there were a few residents left. Emily arrived late and this was not remarked upon. She was given her meal and she sat alone at a separate table. I tried to acknowledge her, but she did not look at anyone and had her back to most of the other residents.

### **After lunch:**

I met Emily on the way to her bedroom; carrying a magazine. I asked her if I could spend a few minutes with her and she seemed to be pleased and invited me to come in and sit down.

I sat on the bedside chair, which was also a commode. *Are you alright sitting on that, love?* I told her that I was fine. We exchanged smiles. She had many ornaments crammed together on the top of her bedside locker and the dressing table. Among these were family photos and I asked her to tell me who they were. She listed the various family members and as she did so located them all in place. For example, *Here is Mathew; he's my grandson who lives in London with his wife and children. He's done well, got a good job and a new car. He's very busy, but he comes to see me when he can. He's got his own family to look after now though.*

*Did you enjoy your lunch, Emily? I asked her. She told me that. It was alright. I don't get that hungry, not in here, like. Then she added, I don't like being with all those people and seeing them all fed like babies. Oh, to come to that. Please – let them shoot me first! I asked her if she had considered eating on her own and she told me, They won't let me. I begged them to let me eat in here, and they won't. It's a rule; we all have to eat together, part of being in the home. So I spend as little time there as I can. Emily sighed and stared out of the window. She seemed to be upset. I got up to go, telling her I would leave her to rest. Thanks, love. I won't be here long. Don't you worry, I'll be able to have me own dinners soon.*

Emily's description of her feelings about mealtimes in Poplar Court captured the way that she saw the act of feeding residents as being an unacceptable part of life in the home. She claimed that she would rather be dead than have to be fed. She also emphasised how she could not escape this public space in which eating took place. For the residents of Poplar Court this was where the 'living' status was most powerfully performed and expressed. In the vignette that follows, mealtimes were also the focus of the communal act of 'living' in a care home.

## **4.4 Vignette 2: 'Living' in Regis Home**

### **4.4.1 General information about the home**

Regis Home was in the centre of the town situated at very busy crossroads. The home had been converted into a 35-bedded nursing home from a large family house. Five years previously, a new wing had been added to provide an extra six bedrooms on the ground floor wing and included a lounge which opened onto the garden via French doors. The

front door to Regis Home was kept locked at all times and visitors had to ring a bell to be admitted by a member of staff. Matron's office was in the main hall and from this office, she was able to see all visitors and staff entering and leaving the home. In this way she performed her surveillance of what was happening to staff and residents in this area, as part of her role as head of home. To leave the home, staff and visitors used a coded-key system, which required staff to remember the combination lock number. In the summer, when the French doors were kept unlocked, visitors and staff used the garden entrance to the new wing of the home, rather than the main one. This meant that from her office matron could not see who was coming or going. Access to the new extension and the original home was either by a corridor, which circumscribed the home, or through the kitchen that was a much quicker route. All bedrooms in the older part of the home were upstairs and accessed either by a large sweeping staircase, or a small lift. This reduced the ease with which residents could access their own rooms.

In common with all of the homes, the lounge was the public face of the home and being present in public spaces of the home was part of the membership of 'living' for home residents. This connected the activities in space with the time that events happened and residents were more likely to be in certain parts of the home at certain times of the day. Indeed, residents, once they were dressed and up, seemed to spend most of their time during the day in the lounge areas, which were often called 'dayrooms' by the staff. Regis Home had three lounges; the lounge in the new wing was the biggest and accommodated those residents who were 'continent' of urine and faeces. The other two lounges, in the original part of the home, were larger and one of them led through to the dining room. This was where confused and incontinent female residents sat. It is also where any entertainment took place. However, the second lounge in the original part of the home was quite small and was where the three male and one female residents sat. The home had two dining areas, one in the extension and the other in the original part of the home, and both were at one end of a lounge area.



Matron allocated particular areas of the home, and therefore specific residents, to care staff and she changed these allocations on a monthly basis. I asked matron and the staff about this allocation and she gave me four reasons. First, to make sure that the staff knew all of the residents; second, that they did not get too attached to certain residents; third, that they did not have to care for any residents they did not get on with for an indefinite period of time and fourth, to prevent what she called 'uneven' workloads. By this, she meant residents who were in need of a higher level of care. The staff I talked to told me that they liked the system of rotation and echoed the reasons which matron provided.

At the time of admission to Regis Home, which was a nursing home, residents were categorised as being in need of nursing care. Most of the residents in the home were in need of a high level of personal care and all of the residents were washed and dressed and helped or taken to the dayrooms (usually in a wheelchair) on the ground floor. In this way time and space were fused into the institutional structure of 'living'. In the morning, the day staff began their shift by listening to the report and then getting the residents up and dressed. Washing and dressing residents took most of the time in the morning, but the staff tried to get the residents to the dayrooms by 11 am. Matron told the staff when to go for their coffee break and carefully monitored how long they took. For example, I observed that she looked at her watch before they went and when they came back.

Matron told me she thought mealtimes were a very important part of the life of the home and that the food should be well served and of a high quality. At about 12 noon those residents who were more dependent were taken to the dining tables and seated for their lunch. The dining area was cramped and, therefore, residents had to be taken to their table in a certain order. Those who were in wheelchairs were often seated at each end of the table and had to be taken either first or last. In addition, residents like Millie, who had dementia and who did not sit still for long, had to be returned to the table

several times. I noted that the task of seating four residents at each of the five tables took up to half an hour.

After lunch, residents were taken to the toilet. The home staff called this 'toileting' the residents. The heavy residents, those who were overweight and those who were unable to lift themselves, were lifted onto a commode in their bedroom using a hoist. Some of the residents had soiled clothes, which had to be changed. Those with visitors had to be 'toileted' and 'changed' and taken back to the lounge to see their visitors but many of the residents were taken to their room for an afternoon rest. This part of the work was very heavy, and there was a lot of pressure to get the job done quickly and I noted that the whole process of 'toileting' and changing residents took about an hour.

I would argue that this was another enactment of institutional life through the control and regulation of bodies in time and space. I argue further that in the performance of these activities, the body of each ageing resident was being made to 'live' and as such, conform to a residential construction of 'everyday life'. I would argue that these are the routines and practices of institutional life that Goffman (1968) claimed as part of the rational plan which regulated the institutional life of the residents.

#### **4.4.2 A confused form of 'living' in Regis Home**

The account that follows is reconstructed from my fieldnotes. Millie was incontinent of urine and frequently wet. Her wandering and the smell of her urine soaked clothes added to the strong smell of urine that pervaded the entire home, but which was most striking in the entrance hall and the bedrooms. At mealtimes, in particular, the smell of urine mixed with the smell of food. The example of Millie, who had lived in the home for four years, highlights the need to keep her safe by watching and containing her. The account that follows shows how home staff used two ways of framing Millie's embodied activities; those of living' and being a nuisance.

### 4.4.3 Observations of Millie

When I asked the head of home to tell me about Millie, she described her as a 'fixture' of the home. This suggests that Millie was permanently liminal to the home. Most of the times in which I visited the home, Millie wandered around the hall behaving as if she was tidying and inspecting the home. For example, the first time that I met her she was checking the banisters for dust, by running her fingers along the paintwork. The staff explained to me that Millie used to run a small hotel and in her confusion, thought that she still did. Millie's speech was confused, her words ran together and she repeated many sounds. As a consequence, it was difficult to understand what she was saying. By the way that the staff interpreted what Millie was doing, it seemed that this previous life was being partially reconstructed by the staff in Regis Home. I would argue that the staff were maintaining Millie's version of 'living' and also containing her so that she did not 'disturb' the rest of the home.

While Millie was allowed to wander certain boundaries were maintained. The care staff always seemed to be aware of where Millie was so that they routinely monitored her and appeared ready to steer her out of any forbidden areas, in which she often appeared. She spent most of her time in the entrance hall and was frequently drawn to matron's office; when matron was present she either shooed Millie out of the room or tolerated her. Matron's office contained the records of the residents and the drugs trolley and was also where the report was given. Whenever she was on duty matron spent a great deal of time in her office.

In the following account, taken from my fieldnotes, I illustrate the way that Millie, as a 'confused' resident, was contained. On this particular day matron was showing a visitor around the home, I was given the task of 'watching' Millie. Millie was having 'one of her off days' and the staff told me that she needed to 'be watched'.

### Fieldnotes: The containment of Millie

I walked along with Millie up and down the hall and in and out of the small and large lounge. Millie sat down in one of the lounges at one point and one of the residents shouted at her to *get out of that chair. It's not your seat!* I persuaded Millie to get up and she insisted on going into matron's office. I knew that I must prevent 'my charge' from doing damage but I found it very difficult to persuade Millie to leave. On this occasion Millie became quite aggressive with me and pushed me away when I tried to touch her. She proceeded to tear up some of the papers on matron's desk. I was anxious and sought help from a care assistant. The care assistant left what she was doing and came with me to matron's office. She told me I had to be 'firm with her when she's in one of her moods'. Then, I was shown how to be firm with Millie as the care assistant lifted her by the elbow, raising it high and almost pushed her along, ignoring Millie's clear sounds of protest. *Come on – out of here!* she commanded Millie.

The above snapshot of Millie's life in Regis Home highlights several aspects of the way that 'living' was constructed. Millie was not invited to participate in the main social events of the home, with the exception of eating with other residents, which I consider next. Millie was a resident who had no problems with walking unaided, as most of the other residents seemed to have and I was struck by Millie's ability to move so quickly. However, her label of being 'confused and difficult' meant that staff needed to be careful not to upset her. Therefore, while the staff were controlling Millie's actions by limiting the areas of the home which she was allowed to enter at particular times, they were also recognising Millie's ability to resist their constraint.

#### 4.4.4 Boundaries

I would argue that Millie's life in Regis Home was structured around the management of several types of boundaries. Millie was taken to the toilet on a regular basis, but during my observations, she did not pass urine when she was put on the toilet, and instead, would wet her clothes. Consequently, she had to be changed several times a day. I would argue that her leaking and smelling body, her continuous talking, making of sounds, and some verbal abuse and her physical wandering around the home were all signs of resistance by transgressing boundaries. I also argue that her urine constituted 'dirt', and as such, matter out of place (Douglas, 1984) that transgressed the institutional norms of the home, here keeping ageing bodies clean and dry.

The way in which Millie was able to wander around the home quite freely, contrasted with the immobility of other residents. Millie's confusion and her incontinence made her difficult to contain. Millie's form of 'living' highlighted the boundary between care and control, which the staff tried to manage. However, because Millie had been identified as a resident who needed to be contained as part of her care, this boundary between care and control was, at times, seamless. The sedation which the staff used through regular medication was a chemical form of constraint. At night, when Millie was confined in her room she was sedated, while during the day she was always present in the public and 'living' spaces of the home.

On one level Millie had lots of territory in which she was allowed to roam, yet she did not seem to have a place of her own in the 'living' areas of the home, except at mealtimes. Furthermore, for residents like Millie, being in the 'old' part of the home meant that they were not able to choose how they spent their days but were expected to conform to a status of living that had been allocated to them. However, Millie's confused state meant that she was either not invited to participate or was excused from some of the activities of rehabilitative living, unlike Maude whom I discuss in Section 4.4.8.

The way in which the staff responded to Millie and interpreted her need for containment, seemed to depend upon the way they read her mood. The fact that I had been assigned to her and given a watching brief because she was having an 'off day', signalled to me the staff's concern of some sort of danger. During my duties of surveillance and control of Millie, I interpreted that by ripping up the papers on matron's desk, a boundary had been crossed and I felt that I had failed to contain her and sought extra help.

As stated above, a major institutional practice of the routine of 'living' was focused on mealtimes and this is what I discuss next. In this extract from my fieldnotes, I describe how I helped at mealtimes in Regis Home that was one of the main ways in which I was invited to participate in the care in homes.

#### **Fieldnotes: Feeding Millie**

I seated Millie at the table for her lunch opposite Sarah, who was fed all her other meals in the small sitting room which she shared with the male residents. I was asked to 'keep an eye on these two and feed them their lunch.'

Matron was 'doing the medicines' as the care assistants called this task. I knew that Millie was given tablets to 'calm her down' as matron explained to me a few days earlier. Matron approached with the medication trolley. She put two tablets into a small plastic medicine pot and handed them to Millie. *Take your tablets Millie, come on love they're good for you.* She spent some time making sure that Millie had swallowed her tablets.

Matron watched Millie. I wondered if she would ask to see inside her mouth but she did not. In response to my inquisitorial look matron told me, *She sometimes hides them and spits them out later.* Then turning to Millie, *Don't you, love, eh?*

When her lunch was served, Millie ate everything on her plate very quickly and then tried to steal food from Sarah's plate. By contrast, Sarah refused to eat, and most of the time during my observations in the home, had to be persuaded to do so. She was given minced food for her lunch, which she moved around her toothless mouth before she spat out each spoonful that I gave her. I wondered what to do about this. Sarah was so thin that she could weave her way out of the 'geriatric' chair that was meant to contain her. Later, at tea time, I asked the care staff what to do about this and they told me not to worry.

#### **4.4.5 Food and 'living'**

My data shows that one of the most significant features of 'living' was taking part in mealtimes. Staff served the meals and fed residents who could not feed themselves or who did not want to eat. In common with other homes, those residents who normally ate their meals and no longer wanted to eat received a lot of anxious attention from the home staff. However, the example of Sarah highlights how taking part rather than eating, seemed to be important. And, like Sarah, not all of the residents who were fed swallowed their food, but taking part remained an important symbolic ritual that signified the 'living' status of residents. There was an incongruity of putting food into the mouths of residents like Sarah but which she did not swallow, which acted as a powerful representation of life. I argue that the social body of Sarah was being fed, but the biological/natural body was starving to death.

#### **4.4.6 'Living' spaces**

There were several 'living' spaces in Regis Home. 'Living' in each of these spaces was demonstrated differently according to the way that each of the residents were labelled. For residents like Millie and Maude the label of dependency associated with their

allocation to the original part of the home meant that they were not able to choose how they spent their days but were expected to conform to a status of 'living' that had been allocated to them by matron and the care staff. The confused residents, who were immobile, were only involved in basic activities of 'living', those of being placed in 'living' spaces and being fed. They did not qualify for, nor were they included in formal activities of rehabilitation, despite the risks of institutionalisation, which would potentially affect all residents.

As with other homes, the 'living' spaces in Regis Home were also spaces in which residents could be seen clearly by the staff. In the extract that follows I describe the detail of one aspect of this type of regulation and how this comprised part of 'living' through an activity that was meant to produce rehabilitation.

**4.4.7     Maude and the jigsaw**

**Fieldnotes: Regis Home**

Maude sat at the table with her back to the other residents in the lounge and with a jigsaw in front of her. Some residents in the room were decorating hats and this is where June, the activities helper, focused her attention. Maude stared out of the window. I was seated just a few feet away and to the right-hand side of her. The jigsaw was on a tray and about a quarter of the pieces were in place; the rest scattered around the edges of the tray. Every now and again Maude let out a deep, audible sigh. This seemed to remind June to come and look at the jigsaw and ask Maude how she was getting on, which she did three times during the hour set aside for activities. On one occasion when June was with her, Maude looked at the jigsaw and picked up a piece and stared at it. *That's it – you see if that goes somewhere*, said June. As soon as she walked away, Maude stared out of the window again and let the piece fall out of



her hand onto the tray. I approached Maude and asked her if she liked doing jigsaws. *I hate them*, she said and let out another loud sigh.

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#### **4.4.8 Rehabilitation**

As I argued in Chapter 2, I am using the term rehabilitation to denote a practice employed by care staff to attempt reduce or prevent the effects of institutionalisation. The relationship is complex because dependency and autonomy are not necessarily in a direct oppositional relationship as Peace et al argue (1997). I am not arguing against the need for caution within such broad and poorly defined terms, but I argue that rehabilitative activity in those care homes in which I made observations, was more symbolic than meaningful. This example, taken from my fieldnotes, typifies the focus of attention in care homes on 'activities'. As I argued in the literature review in Chapter 2 (Goffman, 1968; Townsend, 1964), the shift away from the potential dangers inherent in institutionalisation, resulted in a deliberate policy of rehabilitating older residents in care homes. I argue that this was one of the key ways in which 'living' in homes was constructed and produced. The appearance of Maude in front of the jigsaw could be interpreted as her 'doing a jigsaw'. The reality was different as my fieldnotes indicate. Maude was immobile and she had to be helped to move from her wheelchair into an armchair, to the toilet and into bed. Therefore, she was unable to move out of the chair where she had been sat in front of the jigsaw. I would argue that, rather than reducing the dependency that can occur in institutional life, the *performance* of rehabilitating Maude was itself in danger of becoming part of the institutionalised aspect of living. In other words, a routine event that did not require Maude to be involved in any meaningful way, but rather to demonstrate the actions of being involved seemed to stand in for the act of rehabilitation. Furthermore, it did not seem to matter that Maude did not enjoy 'doing' the jigsaw, nor that she was unable to place any of the pieces into the jigsaw,

what seemed to be more important was her appearance of doing the jigsaw and that this contributed to the activity session, as part of the overall performance of rehabilitation in Regis Home.

Further distinctions can be made between being entertained, taking part in the entertainment and entertaining oneself. Residents seemed to be categorised according to those who were able to entertain themselves and those who had to be encouraged to take part in some form of occupational therapy. This is something that I return to later in the chapter.

From my observations and conversations, for June and those activities workers I observed in other homes, the focus of activities for those residents who were disabled seemed to be mostly on crafts, reminiscence and games. Keeping residents mentally occupied seemed to be the most important aspect of home activities, in contrast to the physical care that dominated the work of the care staff. In this example, while the focus of care was on the otherwise unified process of 'living', reproduced through forms of care which addressed the body such as washing, eating and 'toileting', here rehabilitation was focused separately on the mind. There were also residents who were not considered by the staff to be capable of taking part in the activity sessions, and these were those residents labelled as 'confused' and 'out of it'.

Also significant was the staff's view that those residents in the new lounge were mentally alert and were given a choice about taking part in these weekly activities. During my observations in the home, no-one from this part of the home chose to join in any of the activity sessions. However, when there were special events, such as birthdays and Christmas, there was an expectation that all residents who were well enough to do so would participate. 'Living' in Rugby home took place in different spaces of the home; residents seemed to be allocated to the different lounges according to their mental awareness. The account that follows includes a different form of 'living' which I have called 'liminal'.

## **4.5 Vignette 3: 'Living' in Seaview House**

In this vignette I highlight the routines and practices of a small residential home in which the residents were given more choice about what they do each day. In contrast to the previous two vignettes, these residents were less frail and more able to care for themselves by washing and dressing. When I interviewed the head of home, she told me that she considered that residents should be afforded as much dignity as possible and should be enabled to make their own choices about the extent to which they were involved in the community of the life of the home. She regretted that most of 'her' residents kept themselves separate and spent most of their time in their own rooms, rather than the lounge and garden. During the time that I spent there, the lounge remained largely empty and the garden unused.

### **4.5.1 Background to Seaview House**

Seaview House was a small private residential home in the North West coast of England situated in a road that ran down to the sea. This spacious and attractive house boasted large gardens front and rear with views of the sea from the upstairs rooms at the back of the house. The home owners, a nurse and sea captain, bought the house when they both retired early from their respective occupations.

The house contained much expensive-looking antique furniture. It did not smell of urine or the air freshener that was frequently used to camouflage less pleasant smells. The home had a small lobby and a large central hall with all rooms and stairs off. The lounge contained a dining area and a sun lounge – with views of the garden and the sea beyond. At the side of the house was a small extension with two large double en-suite bedrooms. Tom, one of the residents lived in one of these rooms.

The extracts that follow describe two residents in Seaview House, Tom and Grace. They are compiled from fieldnotes taken over several days, a formal tape-recorded interview with Tom and conversations with staff and other residents.

### 4.5.2 Tom's life in Seaview House

In Seaview House I spent most of one day with Tom, a resident who had lived in the home for the past eight years. Tom's day started with his breakfast in his room. He liked to rise early and would be waiting for his breakfast when it arrived. He then went for a walk along the beach. Tom went out every afternoon to various clubs and to adult education classes that were run locally. Tom's room was situated at the back of the house and contained many his own possessions including furniture. He invited me in for a chat and showed me all of his possessions. The room was full of books, ornaments and photographs. Tom also got out some photo albums to show me photos of his family.

Tom's wife had dementia. She used to live with him in Seaview House and now lived in a home a few miles away that specialised in the care of people with dementia. He told me that, one day after his son had taken him to see his wife, the staff of this home told Tom that she would only 'get worse'. Tom's wife no longer recognised him and Mrs. Stoney, the matron of Seaview House, told him that it was not worth while visiting anymore. Tom told me that he agreed that visiting his wife was too upsetting and that he should not do this any more. He recounted to me that matron had told him, 'She is dead to you now Tom'. He said that he found this helpful.

Lunch was taken at 12.30 and this excerpt from my fieldnotes describes the day I joined the residents for lunch.

#### **Fieldnotes: Lunch at Seaview**

I was invited to join the residents for lunch and as residents arrived at the table, they moved to accommodate each other. For example, the head of Home moved a chair so that someone with a frame could sit down more easily. Tom pulled out the chair for Mrs. Hayle. Mr. Jones arrived at the table shuffling into the frame that he seemed to have to throw forward with great effort. He was out of breath. He looked very thin and his feet

were so swollen that they hung over his shoes. He made his way to the table very noisily and muttered and groaned. Tom offered to help him but this offer was refused. (I interpreted these as signs of concern – although there was no evidence of any companionship in the home). There were eight of us seated at the table and we were served by Mr. Stoney who had also cooked the meal. We were offered wine with the meal and Tom told me that this was in my 'honour'. The residents did not talk to each other beyond an initial greeting. However, after everyone had a glass of wine they made attempts to talk to each other. For example, Mrs. Hayle, the 'new' resident, who I knew had worked as an interior designer and a window dresser, told me that everyone has a different view of the truth. Tom joined in and told me that I was affecting my research through the 'Heisenberg' effect. He added, *This is very unusual – the meals are often taken in complete silence.* Mrs. Hayle joined in, *Artists even see different worlds from each other.* After lunch everyone returned to his or her own room. I was left sitting alone in the residents' lounge writing these fieldnotes.

The focus on the social dimension of meals at Seaview House contrasted with other homes that I observed. Indeed, in Seaview House, the dining room was the only room in which residents were expected to share space in the home. I argue that this was where the social aspect of being a resident was played out. Furthermore, rather than feeding the residents and being positioned as separate from them, my role was interpreted as one of participating in what the residents did, rather than participating in what the staff did to the residents. While the emphasis of meals and eating as a part of 'living' was interpreted differently, in Seaview, in common with the other homes, mealtimes shared the same feature. They served as markers of time and residents of Seaview House were all expected to make an effort to attend the dining room for lunch. Rather than serving the

sole function of taking part in meals as a feature of 'living' with food as a biological symbol, the performance of a shared meal also served the social function of being part of the same community of 'living' residents in Seaview House.

The story that follows is of an exception to the membership of 'living' residents at Seaview.

### 4.5.3 Grace's story

Grace lived in one of the downstairs bedrooms and was one of two residents who needed nursing care. She could not walk unaided. Mrs. Stoney asked me if I would like to meet Grace and I agreed to do so. First she told me her story (although she had told me already when I first met and interviewed her):

*We call her Lazarus, because she rose from the dead. She is 102 and she was bleeding to death from her vagina. They all gave up on her and I told the family she would die. That was over a year ago and she's still here. You can't communicate with her – she can't see or hear you, but she likes physical contact.*

Mrs. Stoney told me that she supervised all of her care. She then took me into Grace's bedroom. She told me to 'just sit with her' and left me alone with Grace. Grace was in an armchair that resembled a bed. She was lying in a semi-recumbent position and was wrapped up in several blankets. She looked very clean and comfortable. The bed beside her was made up. Grace was very small and emaciated. Just her head and one hand protruded from her cocoon of blankets. She was seated by the window which overlooked the sea – but she was blind. I sat close to her and introduced myself, *I am Carol. I am doing some research here. Can I talk to you?*

I was not sure if she had heard me, *Who are you? What are you doing?*

I shouted my introduction again into her ear and she nodded. Grace then asked me, *Is there something wrong with me? I think there is. I don't like to be left here, will you stay with me?*

I took her hand and she gripped it tightly, *I want to go to heaven.*

I asked her why she wanted to and she replied, *Because no-one wants me!*

I have included Grace's story here because rather than someone who was presented as a 'living' resident in Seaview House, she was someone thought to be 'dying' at one point and who did not die. Despite having survived for several years beyond her predicted death, Grace did not re-enter the 'living' spaces of the home. I would argue that instead she occupied a liminal space between 'living' and 'dying'. This liminal; space sutured the difficult boundary between 'living' and 'dying'. The act of getting Grace out of bed and putting her in a reclining armchair positioned her as different from the other residents. The question from Grace about what was happening to her wanting to go to heaven and her belief that she was unwanted provides a poignant example of what it must have felt like to occupy this space between life and death.

## 4.6 Conclusion

In this chapter I have argued that the way in which 'living' in care homes for older people was produced is shaped by the practices and structures of the homes. The main focus was on the physical body of residents. Care staff spent most of their time in washing, dressing and placing these frail bodies in the communal 'living' spaces of the home. Time was marked by meals, getting residents out of bed, washing them, and joining in with other 'living' residents, which included resting and toileting before being put back into

bed. Rehabilitation was a key feature of 'living' for some categories of residents. This included being entertained, either by taking part in activities or observing entertainment. Those residents who had a legitimate claim to social worth set themselves apart from those who did not.

The examples that I have provided of care are mainly focussed on the bodies of residents. The symbolic nature of taking part in meals, through eating or being fed, highlighted the extent to which this was more a production than a biological act of sustaining life through the nutritional value of food.

I have also illustrated examples of resistance, which include, not using the toilet, not swallowing food, not being entertained and not dying when Grace's time seemed to have arrived to die. I argue that the staff's lack of apparent concern about this resistance, to the extent that they continued their practice regardless of its end result, meant that the performances were more symbolic than instrumental. In part they had to respond to the expectations of rehabilitation that were enshrined in policy (as I argued in Chapter 2). From this point of view, it was extremely important that most residents were categorised as 'living'. Alongside this there was a need to maintain the boundary between 'living' and 'dying' residents. This boundary, blurred by the chronic condition of failing and ageing bodies was not easy to maintain and the bodies of residents became increasingly resistant. There was a point at which the unravelling of these frail bodies could not be contained within the category of 'living'. How they transgressed the boundary into 'dying' is what I turn to next.



## CHAPTER 5

### 'A state of dying'

#### 5.1 Introduction

This chapter explores the ways in which staff made predictions about death and dying; the part that residents played in this and how the category of 'dying' entitled residents to a different form of care, while, at the same time, achieving a distance between 'dying' and 'living' residents. I argued in Chapter 4 that 'living' was produced through activities and qualities that were enacted through various routines and rituals performed by home staff and residents. Here I use Goffman's (1962) theory of symbolic interactionism to argue that the status of 'dying' in care homes was *produced*, rather than simply being a response to a biological reality, and further, that how 'dying' was produced depended upon the way that the qualities of the status of 'dying' were attributed and interpreted. Goffman used the term 'total institutions' to highlight how institutions had the power to define the identity of its inmates, and I argued in Chapter 2 that care homes for older people qualify as such total institutions. However, while his argument locates power within the routines and practices of the institution, Goffman (1961) does not discuss the potential benefits that derive from this production of identity, beyond it fulfilling the purpose of the institutional control of inmates. Furthermore, while it is the case that the focus of my fieldwork was on the way in which care staff enacted routines and practices, my data suggest that interpretations of 'dying' fulfilled different needs for all those people with vested interests in knowing when the process of 'dying' had begun, and this included care home residents and relatives.

In care home settings where between one fifth and one third of all residents died each year (Sidell and Komaromy, 2003), death was an unavoidable reality. Whereas younger adults might see death in later life as something 'natural' and 'acceptable', what I observed was individual resident's intense interest in predicting the signs of the imminence of his or her death. In this way, each resident could apply an interpretation of the signs of 'dying' to his or her own potential demise. Therefore, an ongoing interpretation of significant signs of 'dying' in residents in the home included that undertaken by staff, residents and any visiting close family and friends. In the category of staff, I include any general practitioners (GPs) who were involved in the medical diagnosis of the beginning of a period of 'dying'. Indeed, the title of this chapter derives from a quote that is taken from a conversation I had with a GP to St. Mary's House, the context of which I discuss later. I argue therefore, that while staff, residents and visitors were concerned to interpret signs of 'dying' based on different needs, the qualities of 'dying' were co-produced by staff and residents.

Roth (1963) claimed that those patients with tuberculosis, whom he studied in a TB sanatorium, were actively engaged in an interpretation of what was happening to other patients, in order to apply this understanding of events to their own situation, and thus, be better able to both predict their own illness/recovery trajectory and further, to negotiate events. This study, called 'Timetables', was based on the way that the illness trajectory of TB was marked by features that symbolised progress towards recovery. Roth argued that, while the power to define the markers of recovery were located in the medical domain, patients did not act as passive bodies waiting for various qualities to be awarded to them; rather, they participated in the interpretation of signs. Likewise, I argue that residents in care homes were not only engaged in the parallel activities of 'living' and 'dying' but also in an interpretation of these states. For example, during my fieldwork, residents talked to me about their predictions of the death of other residents as much as they talked to me about any wishes and fears they might have about their own death. Therefore, this chapter is not *just* about the way that staff of care homes read the signs

of 'dying' in their residents, it also highlights how this is a reciprocal and interdependent process.

Despite the high premium that was placed on 'living', staff expressed a wish for residents to be able to die in the home and, in this way, to achieve a death which they considered to be 'good' for each individual resident (Sidell *et al.*, 1997). And, part of the definition of a 'good death' given by heads of homes, was that residents would die in the home as it had become *their* home. Therefore, the home staff's capacity to enable residents to achieve a 'good death' partly depended on their ability to predict when death would occur (Sidell and Komaromy, 2003). In Chapter 4, I highlighted how the combination of chronic illness and the need to 'keep residents going' in care homes resulted in a blurred boundary between living and dying, and, within this, the dying phase was narrowly defined as days or weeks. Here I argue that a narrow dying trajectory minimised the risk of identifying 'dying' too early and inappropriately. It follows that, for care staff, part of their task of distinguishing between 'living' and 'dying', was the development of ideas about what qualities they could attribute to each 'living' and 'dying' status.

While the transition into the category of 'dying' allowed for material privileges associated with terminal care to be awarded to residents such as being kept in bed and receiving bodily care and pain-relieving drugs, often tokenistic, as I show, my data showed that, as with 'living', the 'dying' period also fulfilled symbolic functions. My fieldwork observations revealed the extent to which the boundaries between life and death were maintained and the strategies that staff deployed in order to do so. Van Gennep (1960) identified crucial stages of life as rites of passage, including birth, puberty, marriage and death. He argued that, through ageing and illness, individuals withdraw from active life and social contact. Furthermore, that rites and customs serve important psychological, sociological and symbolic functions. I have also drawn on the arguments by Douglas (1984), to explain the symbolic significance of boundaries and the need to keep

'living' and 'dying' categories distinct. However, while the short duration of the period of 'dying', allowed for a more sustained intense period of terminal care, my data showed the arbitrary nature of the categories.

In the following sections I consider how the dying trajectory for older people in care homes was narrowly defined and illustrate the qualities of 'dying' and the way certain features served as signs of the beginning of the 'dying' trajectory. I use two vignettes to explore what followed on from the diagnosis of 'dying', what type of care residents were entitled to receive and how this was different from the care given to 'living' residents. While there was some variation between homes, what they all shared, was the practice of changed routines for a resident once the status of 'dying' was afforded. Throughout, I argue that the way in which the category of 'dying' was constructed served to produce a 'good death' as it was interpreted within institutional life. The performance of caring for dying residents was part of the dramaturgical build up to the death bed scenes that are the subject of Chapters 6 and 7.

## **5.2 Dying trajectories**

In this section I draw on data from the commissioned study (Sidell, *et al.*, 1997) to contextualise the way that dying trajectories in those care homes were constructed. In the literature review, I argued that, according to Glaser and Strauss (1965b), there is a high level of investment in the need to predict death. Further that in chronic illness, combined with old age, predictive markers were less easily recognised and established than in younger people. A diagnosis was also less likely to be medically resourced and sanctioned, and the evidence for the likelihood of death seemed more speculative and less scientifically tangible. Added to this, was the reality that for some residents a form of social death had occurred that made physical 'dying' less significant. Therefore, establishing one or several markers of the beginning of 'dying' in a very slow and gradual decline to death was difficult. Certainly, it was the case that findings from the

commissioned study (Sidell and Komaromy, 2003) revealed that in retrospective accounts of death some deaths had been easier to predict than others, even though residents were on a slow trajectory of decline in old age. The findings also highlighted the ways in which dying trajectories were constructed. In all, heads described 133 deaths and it was possible to categorise them into four main types as the following chart summarises.

**Table 5.1 Classification of types of death in 100 homes**

Type of death – from data on the reason given as cause of death	Percentage of deaths – Total number of deaths 133
General deterioration – no specific marker for the period of dying – but death anticipated	40%
Acute episode as the marker of 'dying	35%
Terminal illness – unambiguous condition – not age- specific	15%
Sudden death – unexpected	10%

In the first category, nearly 40 per cent of deaths were described as part of a process of 'general deterioration', which was sometimes imperceptible, and which had no specific event to mark the beginning of a decline. These residents, who were described as 'fading away', were still assigned to a 'dying' category and given terminal care, although this was often only a few weeks or days prior to death, when death became more clearly imminent. The second most common category accounted for 35 per cent of all deaths and included an acute episode, such as pneumonia or a serious fall, which clearly served to delineate 'living' from 'dying'. The third category, which accounted for only 15 percent of deaths, differed significantly from the two previous ones in that the 'terminal illness'

status was applied to conditions such as cancer or Parkinson's disease, which were not age-specific. In other words, these conditions that might also affect younger people were privileged above less clearly defined dying trajectories, even though the culmination of multiple chronic conditions also led to death. For example, it was more likely that support services could be legitimately utilised for residents with clearly identified and unambiguous terminal conditions and, for example, care staff called upon the services of Macmillan nurses for residents with severe cancer pain, but were unlikely to do so for residents with equally painful arthritis. Likewise, residents with Parkinson's disease were more likely to receive medication to control their symptoms than those with illnesses categorised as age-related. The fourth and final category of 'sudden deaths', accounted for less than 10 per cent of all deaths, but were described as creating enormous distress to both home staff and relatives. These sudden deaths served to explain the felt need for the control and separation of 'death and dying' even in settings in which death was such a regular event. These deaths are the focus of Chapter 7.

### **5.2.1 Narrow dying trajectories**

The table on the next page summarises the retrospective account of the period of 'dying' given by heads of homes at interview on the three most recent deaths that had taken place in the home (Sidell and Komaromy, 2003).

The data that I have drawn on here to describe the markers of dying serve as illustrations of categories of markers that I derived from analysis of the interview data collected during Stage 2 of the commissioned study.

**Table 5.2 Length of dying period in 100 care homes**  
**(N = 133 deaths).**

Length of period of dying – retrospectively categorised	Total percentage of residents in each category
Sudden	9%
Hours	6%
Days	30%
Weeks	40%
Months	12%
Years	3%

(Table reproduced from Sidell and Komaromy, 2003, 'Defining dying' p. 47, Table 3.1)

*Transfer out of the homes*

In Chapter 2, I argued that death and dying for older people is less likely to be medicalised or death postponed. It is important to note, however, that there were circumstances in which residents were transferred out of the home for treatment in hospitals or nursing homes. Statistical evidence from the commissioned study (Sidell and Komaromy, 2003) showed that as many residents were transferred out of homes and who subsequently died as were transferred into home and also subsequently died.

*(C)onflicts arose over whether or not a resident was dying, that is, defined as dying, and, if they were, whether they were in need of medical intervention which the home could not provide. The stated reasons for transferring people to hospital were medical conditions such as myocardial infarction, dehydration,*

*cerebrovascular accident and pneumonia – all of which they felt required more care than they were able to give.*

*(Sidell and Komaromy, 2003, p.51)*

In the sections that follow, I use interview and observational data to illustrate what happened after a marker of 'dying' was attributed to a resident as the beginning of the 'dying' trajectory and discuss specific markers of 'dying' as illustrations of how these were interpreted.

### **5.3 Markers of 'dying'**

When residents were considered to be 'dying', I was keen to explore any existence of the practice of moving them into a separate part of the home, which had been the case in Hockey's study (1990). This was what I had anticipated as one of the likely practices in homes. However, in one interview with Meg Johnson, the head of Poplar Court, she told me that the practice of moving sick residents into bedrooms on the same corridor, so that they could more easily observe and attend to their needs, had ceased, and went on to explain how she had discovered that the surviving residents referred to this corridor as 'death row'. In none of the homes in my fieldwork did I observe the transfer or separation of 'dying' residents into particular spaces set aside for their care. However, it was clear from talking to staff that, when a resident who was thought to be 'dying' shared a room, the 'non-dying' resident might be moved out of that bedroom, either at the terminal phase of 'dying' or at the moment of death. Furthermore, several members of staff suggested that having a 'sick bay' would be one way of overcoming the problems of having to care for 'dying' residents in the home.

#### **5.3.1 The separation of 'living' and 'dying' residents**

While my data suggest that the practice of separating 'living' and 'dying' residents by moving such categorised residents into 'dying' spaces had largely ended, 'living' and



'dying' residents continued to be kept spatially apart. For example, I noted that 'dying' residents no longer shared the public spaces of the home and instead were kept in the more private space of their bedrooms. This absence resulting in the empty space previously occupied by a 'living' resident, served as a sign of his or her transition from the status of 'living' to that of 'dying', and therefore, the spatial separation allowed for everyone involved in the home to read this absence as a sign of 'dying'. I would argue that a sustained lack of presence in public spaces of homes was a clear marker of 'dying'. Therefore, in this way, the absence of the qualities of 'living' suggests that this could serve as a sign of 'dying'.

In the previous chapter, I argued that the activities of 'living' were produced in public spaces of the home. Here I argue that one of the first signs for other residents that someone was ill and possibly 'dying' was when he or she did not appear in the public spaces of the home. It was something that residents remarked upon, both during my observations and in listening to residents' accounts of the death of another resident. For example, Lucy, a resident in Autumn Lodge, told me about the first time that she noticed something was 'wrong' with another resident, called Mary, with whom she was friends.

*She didn't come down to breakfast which was not like her, you know? Then she didn't make it for her lunch and I thought to myself, like, oh erm, there's something wrong here. I asked Jane (the care assistant) and she said, 'She's not so good today Lucy.' I knew it were more than that, though!*

This account by Lucy suggested to me that Mary's absence from her usual space in the home, in this case, the dining table, was something that she interpreted as being significant. I have argued that in a spiral of gradual but uneven decline, which is the case for many older and frail residents, the boundary between 'living' and 'dying' was not easily demarcated and, therefore, predictions were difficult to make. Keeping death concealed as part of the focus on life resulted in seemingly inevitable contradictions within performances around 'dying' and 'living' residents. Furthermore, I argue that making an

overt and explicit separation between 'living' and 'dying' residents was problematic in settings where death was viewed as the 'natural' and timely outcome of a long life.

During my fieldwork, I heard staff and residents refer to vacant chairs as belonging to a particular resident. In this way, the surviving home residents were marking the space of an absent resident and participating in the activities associated with the production of 'dying'. It would appear that one of the strategies to cope with this was to keep 'living' and 'dying' residents physically apart, not via 'dying' spaces, but instead in the 'private' spaces of the home – usually the 'dying' resident's bedroom which then could be transformed into a sick room. Separating 'dying' residents from those who were 'living' was the first significant change in the routines and practices of care homes that marked the beginning of the 'dying' process. I have argued that making predictions about death and dying was in the interests of everyone in care homes and that this was something that was co-produced by staff and residents. However, it might no longer be the case that there are special 'dying' spaces in homes - yet the separation was one of the first responses to 'dying'.

In the next section I consider how, other than as an absence from those spaces designated as 'living' ones in the home, being in bed was another significant marker of dying.

### **5.3.2 Staying in bed – 'dying' space**

In Chapter 4, I described the way that the production of 'living' as rehabilitation occupied the main part of the work of care staff, so that by lunch time all residents would be in the public arenas of the home, either presenting themselves, or being presented by the staff, as 'living', and therefore, ready to eat or be fed. This made being out of bed one of the essential features of 'living', which residents and care staff demonstrated and co-produced. While there is a clear distinction to be made between those residents who were able to get up and dressed themselves, and those whom the staff had to help, this degree

of ability did not in itself define one of the qualities of 'living'. Not to do so for a resident who usually got up out of bed, could be interpreted as a sign of 'dying', as the following quote by the head of Peacehaven shows.

*CK: So tell me, how did you decide that Florence was dying?*

*Lin Brown: Possibly about a month before she actually died. She just lay in bed really; she didn't want to do anything. It was just a case of wanting to keep her fluid intake up. We just didn't want to get her into hospital because we didn't feel she would benefit from that. We did speak to the niece and say that she was deteriorating; do you want us to get her into hospital? And she said, 'No. She's been here so long.' Obviously we called the doctor in.*

This brief account of the last few weeks of Florence's life involved the staff in taking a decision about the possibility of transferring her to hospital. Lin Brown told me how the home staff chose to keep Florence in the home to die. I have discussed the way that, most commonly, residents were only transferred out of the home when it seemed likely that they could be successfully treated or, in extreme cases, when the staff could not provide terminal care. In this example, because Florence was thought to be dying, the decision was made not to transfer her. The head of home indicated that, because Florence 'just lay in bed' she was 'dying'. This was significant as it marked a change for someone who had been a relatively active participant in 'living' activities. However, the head of home by 'keeping up her fluid intake' was letting me know that she was still treating Florence.

In my data I noted how in the retrospective accounts from staff and other residents, those residents who had been able to move around and who were no longer capable of independent moving were 'marked' as having suffered a severe and possibly irreversible change. I argue that this change from an established way of behaving served as a marker of 'dying'. Furthermore, as I will show from my data, the way in which 'dying'

was produced could be seen as a circular process whereby certain qualities of 'dying' were attributed to individual residents and their condition was then interpreted on this basis.

### **5.3.3 Not taking part in meals**

Other 'non-living' signs could be attributed to those residents who did not take part in meals, either by not eating or not being fed. As stated earlier, those residents who were seen as able to feed themselves and 'interested' in food, caused concern to the home staff and any visitors, when they did not want to eat. I have already discussed the symbolic nature of non-nutritional eating that took place as part of the construction of 'living'. The concern was not that residents who stopped eating would die from a lack of nutrition, rather that not eating was a sign and not a cause of death.

There is a legal requirement for people in the UK that they should have been seen by a medical practitioner within 14 days prior to their death, to avoid the need for a subsequent enquiry. In Chapter 8, I will discuss the difficulties that are associated with unexpected deaths. It is enough here to note that home staff were very concerned to avoid the need for any death to be reported to the coroner. One way of avoiding this problem could be making sure that a medical practitioner saw the resident. In the next section I discuss the significance of a medical diagnosis in marking the beginning of the dying trajectory.

### **5.3.4 The medical diagnoses that marked 'dying'**

In the above account, Florence was described by the head of home as both 'fading away' and 'deteriorating' and, while I argue that the process of 'dying' in care homes is less medicalised than in hospital settings, the need to formally diagnose the beginning of the process of 'dying' was an important part of the co-production of 'dying' performed by the carers, visitors and other residents as I will show. Also in that account, the head of home used the word 'naturally' as if sending for the doctor was an uncontested part of

confirming the process of 'dying', even though, from what she had told me, she did not think that the hospital could do anything for Florence. I would argue that, for Florence, the medical diagnosis served to confirm the staff's own prediction of the beginning of the 'dying' phase.

By contrast, Danny, a comparatively young male resident aged 67 years, at Regis House had been considered to be 'dying' over a period of months. Eight months after Danny died, I visited Danny's wife, Lauren, at her own home and talked to her there about his death. There were several events during his illness trajectory that made Lauren think that Danny was 'dying'. The following account from Lauren describes the first of a series of markers which she interpreted as significant:

*LM: And I thought then, I don't know he's going, you know, and that he was going down. And I thought, 'Oh golly, you do look frail', you know, because he was a strong person. But I thought then that he wasn't getting much better, you know? But he seemed to go down from then.*

*CK: Was there anything particularly happening that made you concerned about him?*

Lauren described how Danny had changed his routine from sitting in the residents' lounge to going to bed to lie down in the afternoon, marking a change in his routine behaviour. She concluded this explanation with the following comment, which referred to Danny's gangrenous foot; something she was not aware of until just before he died.

*LM: I mean, didn't know about his foot either. (Long pause while Lauren closed her eyes and seemed to gather her thoughts). I mean I didn't know about his foot 'till just a couple of weeks before he died. I didn't know his foot was like that, nobody told me.*

Lauren followed this account with a description of the moment at which she knew that Danny was definitely going to die and used pneumonia as a metaphor for death. Lauren's retrospective account of Danny's death in the nursing home shows how the signs that

marked dying were not 'universal' since the staff and Lauren placed different interpretations on their significance as features of 'dying'.

*LM: Well, I didn't think he was getting any better because they said he had a chest infection. But when I looked at him, I thought it was pneumonia and I thought, 'Oh golly, I bet he's – you know – this is the end – or the beginning of the end. Because, you know, people that are ill, or been ill for a long time, they don't always die of the – of what they're ill with. They die of pneumonia, don't they?*

*CK: Mmm.*

*LM: And I sort of guessed that he hadn't long to live, you know. But they made him very comfortable. In the last period, they came up every half hour. And they were feeding him liquid drinks.*

This account from Lauren conflicted with those accounts that I heard from the home staff who considered that Danny might live and, therefore, transferred him to the local hospital for specialist advice and management of his gangrenous foot. For example, home staff told me that they did not think that Danny was dying because, as the youngest resident in the home, he was too young. Chronological age, as timeliness, was an essential feature of the 'natural' death at the end of a long life. Lauren's translation of the term 'chest infection' into 'pneumonia' and, for her, its associations with death, suggested to me that there were different signs being read from similar information. I would emphasise the difference in opinion between the staff and the wife of a resident about what counted as a sign of the beginning of the 'dying' period, and the power which conferring a medical diagnosis had on confirming what Lauren thought to be the case.

For many residents, it was difficult to 'discover' many clear bodily signs that they were dying since theirs was a path of general deterioration. I argued earlier that the deaths that occurred in homes often followed a slow deterioration and, as such, residents were not subjected to the diagnostic medical tests that a younger person might receive. The

pronouncement of a doctor, even in the absence of any medical 'evidence' was a common marker of the beginning of a period of 'dying'. In this way, for Lauren, it seemed that she was part of the negotiation of 'dying' in that the interaction between the information which she received, combined with her own interpretation of what she looked for, persuaded her that her relative was 'dying'. This suggests that on one level, information, although carrying a high level of significance, was still subject to interpretation and was often placed alongside other information that was significant to its interpreter. On another level, the medical information, in the form of the doctors' announcement, seemed to carry a lot of weight and made each of the relatives look for confirmation of what they interpreted this to mean.

The following example is taken from an interview with the head of Church House, who lived in the home and was, therefore, on call at night for any help that the night nurse might need. She described a medical diagnosis that she interpreted as a marker of 'dying'.

*She had a stroke, CVA<sup>2</sup> and – a very large one – and unfortunately she lingered for about a month. Full nursing care, similar to Ted.*

There are several interesting points about this brief extract. First, while it is the case that many people make a recovery from a stroke, for this resident the stroke, which was called 'a very large one', served to indicate that a catastrophic event had occurred. The head of home's assertion was underpinned by an assumption that after a 'large' stroke, which qualified as an acute episode and, as such, a clear marker of 'dying', there would be a rapid decline into death. Second, the use of the word 'unfortunately' suggests regret that this resident's period of dying was protracted. The regret could also refer to the amount of care that this resident required, 'full nursing care', which would have been difficult to sustain in a small home such as Peacehaven. Furthermore, because this death followed

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<sup>2</sup> CVA - Cerebro-vascular accident.

Ted's death, another resident who also needed a lot of nursing care, there would have been no respite for the staff. Deaths in care homes were not necessarily spaced over a period of time and even in small homes, with a comparatively low death rate, two deaths close together could make considerable resource demands. The need to be able to marshal scarce resources, and the timing of deaths so that they did not consume all of the resource, further explains the staff's reasons for their pre-occupation with the prediction of 'dying'.

## **5.4 Summary of the markers of 'dying'**

The accounts from staff and relatives of deceased residents provide examples of events that marked the beginning of 'dying' in residents who were expected to die a 'natural' death. The investment in being able to make predictions about 'dying' for specific residents enabled home staff and residents to make preparations and to provide terminal care to residents as an essential part of the realisation of a 'good death'.

I have described what aspects of change marked the beginning of dying and have included events that could be classified as medical conditions, often associated with end-of-life illness, such as stroke and pneumonia. There were also behaviours less associated with social participation, or its absence, such as staying in bed, or being unable to get up; not eating and needing to be given liquids.

Apart from medical events, it is not surprising therefore, that one of the most common predictions of death which staff made was when residents stopped eating. In itself, this was not a sign of 'dying', since many residents had no interest in food, rather it marked a significant event for particular residents. In this way, and despite commonalities, the signs of death were individualised, rather than being universal and intrinsic, in that they were read within the context of other attributes of the resident's physical and social history. Furthermore, without any medically sanctioned reason for not eating such as a specific illness, staff sometimes interpreted the refusal of food as



something that a particular resident had willed and in their words, residents were 'wanting to die' or 'giving up'.

As with the account of Florence, another common marker that signalled the start of the process of 'dying' was a significant decrease in mobility. This was despite the reality that many residents were unable to move independently and had to be helped out of bed, dressed and washed, as discussed in Chapter 3. In the next section I focus on more detailed accounts taken from the fieldnotes on direct observations. In the first vignette I return to Regis Home. In Chapter 4, I provided the environmental context for this home and so it is not repeated here, whereas for St Mary's House I introduce the home and its context.

## **5.5 Vignettes of 'dying' – observations of its production**

I have chosen these two examples because I was present in each home at the point at which a diagnosis of 'dying' was made. Furthermore, the culture of each home was different in its attitude to death. Regis Home was run by a matron who had worked in the NHS for many years and who subscribed to the importance of discipline for her staff. It was clear that staff followed her 'orders' rigidly, at least when she was present in the home. Consequently, it was matron's view that prevailed about the type and quality of care that would be given when a resident was 'dying'.

By contrast, in St Mary's House the subject of death and dying was much more a part of the everyday 'living' in the home. Residents, most of whom were Catholics, were more likely to have chosen to live in St Mary's House because of its religious facilities and the presence of nuns to care for them. St Mary's House contrasts with the other seven homes in the thesis for several reasons. The residents saw their 'life' in the homes as a preparation for death and so death and dying were not such taboo subjects as they were in other homes. This generalised statement needs to be qualified, because there were exceptions in St Mary's House to the willingness of residents and staff to talk openly

about death and dying, though it was more likely that people would do so. For example, when Sister Margaret introduced me to the residents and staff at the beginning of my fieldwork, she did so as, 'Carol, who is researching death and dying'. Conversely in other homes, I was cautioned by the head of home about the need to be very careful when introducing the subject of death and dying. On several occasions, as I sat in the open corridor area to write up my fieldnotes on each of the floors, residents approached me and asked to talk about death and dying. Early on in my field work in St. Mary's House, four residents queued to talk to me about death and its meaning to them. From this experience I was interested to see how a 'dying' resident would be cared for.

### **5.5.1 Vignette 1: Alice 'dying' in Regis Home**

#### *Summary of fieldnotes*

Alice was an alert and articulate resident who had lived in Regis Home for 12 years, since she was 78 years old. I spent a lot of time with her during my period of participant observation in the home and we talked at length about her life and her reasons for choosing to live in Regis Home. Alice now had to use a wheelchair to mobilise and was dependent on the staff for many of her personal care needs. Although she had been able to live relatively independently for most of her stay in Regis Home, she had gradually lost her mobility and was in a great deal of pain from a poorly perfused leg, which caused her a lot of concern. Attempts by her GP to control this resultant leg pain were not successful, and it seemed to take a long time between adjustments of the analgesia.

It was clear to me that the staff were very fond of Alice and matron was particularly close, having known her for the past 9 years. Matron and the kitchen staff had begun to make preparations for Alice's 90<sup>th</sup> birthday due in a few weeks time. For example, a clown had been booked for the afternoon and food was gradually being prepared and stored in the freezer. A lot of the residents were close to Alice and one

resident in particular, Martha, had become a close friend. They found great comfort in sitting together and often held hands as a form of comfort.

Staff expressed concern about Alice's loss of appetite but her continued visits to the hairdresser within the home, and her very smart appearance, seemed to me to contradict any conclusion that Alice had 'given up' caring. During our conversation however, Alice quite often returned to her fear of having to have her leg amputated, which is what had happened to her father. Added to this, Alice had suffered several bereavements in the previous few weeks. For example, Alice's niece, who was like a daughter to her had also died and, more recently, her sister had died in hospital without Alice being able to visit her and say good-bye.

Alice still received visits from close friends and her nephew, the husband of her favourite niece and her closest relative. Alice told me that her nephew was also 'grief stricken', and trying to cope with the loss of both his wife and mother. One day she told me, *I'm ready to die and I want the Lord to take me and I pray each night that the Lord will take me.*

One evening Alice became very ill and was considered to be 'dying'. The head of home contacted me as I had not intended to be in the home that day, and told me that the GP had visited and diagnosed Alice as having suffered a stroke. Matron asked me if I could come and sit with Alice and I agreed to do so. When I arrived at the home, I went to see Alice straight away. I noticed that she was in bed and looked very pale. However, she freely moved both arms. I wondered how the diagnosis of a stroke had been made, since one key symptom would be one-sided paralysis. When I spoke to matron she told me that the GP had ordered 'TLC' (tender loving care). This term was often used as a euphemism for not giving any active treatment as an attempt at a cure, and thereby, to reverse the 'dying' process. She also told me that Alice could not speak coherently and was asleep most of the time.

### Extract from fieldnotes – Regis House

Matron had drawn up a new care plan. Alice's bed was against the wall and the staff had to pull this out when they routinely turned her to the other side, which they did every two hours. Alice had difficulty in swallowing and this frustrated the staff's attempts to give her fluids, even through a syringe. The prescribed Oramorph to relieve Alice's pain was likewise difficult to administer. The staff did not sit with Alice, although they expressed an intention and a desire to do so. Instead they visited her every 15 to 20 minutes.

When I talked to the residents in the lounge in the part of the home in which Alice sat most days, they expressed a lot of concern and shock at the 'suddenness' of her illness. Martha, in particular was tearful and told me she was, *praying that she lives, and doesn't leave me.*

I went into the bedroom and sat with Alice. In the evening, at 8.30 pm when the staff nurse in charge came into the bedroom, she asked if Alice was in pain. Alice nodded a vigorous yes. *You've got a bit of pain have you? I'll see if I can get you something,* said the nurse. This senior staff nurse told me that Alice's screams when she was moved were 'her fight against death'. She did not return. At 10 o' clock matron came and turned Alice onto her other side causing her to scream out again, and then administered the (Morphine) pain-killing intramuscular injection into Alice's buttocks.

I followed matron out of the room and asked her how she thought Alice was. She told me that she thought Alice would live 'a few more days'. At about 11.30 pm I decided to go home and return early next day. I told the night staff that I wanted to be there and see what happened when Alice died and they agreed to call me if there was any further deterioration, or if Alice died.

When I visited the next day and talked to matron, she told me that there had been a slow deterioration during the night and Alice's breathing was more laboured. She called this the 'death rattle'. I went to see Alice, and, although she was less responsive than the day before, she appeared, at times, very agitated and still screamed out when she was moved, even though a care assistant told me she was 'more peaceful'.

Alice was given Oramorph<sup>3</sup>, by mouth through a syringe after she was turned, rather than before and in small and frequent doses. Apart from the GP's daily visits no other specialist professionals were called in.

I leave this account at a point which is hours away from Alice's death. In the next chapter I continue the account of Alice's final day in Regis Home and what happened at and around the time of death. The medical event, described as a stroke, which marked the beginning of the dying trajectory for Alice set in motion a change of routine and practice which differed from that of 'living' care. The first step was the recognition by matron of a significant marker of 'dying' and her call to the GP to confirm this view. I had some difficulty in understanding the diagnosis and spent time reflecting on why getting this 'right' was so important to me. I concluded that my many years of working in acute medical settings had conditioned me to the need to be able to give an accurate diagnosis. It was some time before I could come to terms with the irrelevance of this accuracy. Indeed, in the absence of any intention of 'treating' Alice, an accurate diagnosis was unnecessary. Rather, I realised that its relevance to this thesis was that a medical name had been given to an event that had marked a sudden and dramatic deterioration in Alice's condition. It was its process of medical sanctioning of 'dying' that served to trigger

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<sup>3</sup> This is the recommended form of pain relief and believed to be more effective than a larger dose that is given less frequently.

the response to give Alice terminal care that was most significant. Indeed, after the GP's visit, matron wrote down a care plan that the staff were expected to follow and also contacted me. By awarding a medical diagnosis of 'dying', which had afforded Alice the privilege of terminal care, Alice's care changed from 'living' care to 'dying' care, which involved a different set of routines and practices, as defined and written down by matron.

Finally, the physical care that Alice received was focused on several dimensions. The focus was on her body and preventing any pressure sores developing. The staff carried this out to the extent that, even though it clearly caused Alice a lot of pain to be moved, movement took precedence over her discomfort. I described how the senior staff nurse interpreted Alice's screams of pain as her resistance to dying. Although Alice was being given Morphine, a particularly strong analgesic, it was ineffective in relieving her pain. It is unlikely that the dose and the method of administration would have been anything other than tokenistic. Rather like feeding residents who are unable to swallow or absorb food, so I would argue that the administration of Morphine was also symbolic in that the main concern was much more about the act of giving pain relief, than effectively relieving pain. Alice was given sips of water, but no attempt was made to feed her.

Despite the rhetoric around the need to sit with 'dying' residents, the practice was to visit at regular intervals. I had heard from many heads of home that part of what made a good death was that the resident was not alone. This was part of the rhetoric of a 'good death' and, consequently, I wanted to explore the practice of sitting with 'dying' residents. I had already been asked to sit with another resident who was 'dying' and I have discussed the ethical issues that surrounded this type of decision in Chapter 3. The reality of practice in Regis Home was that care staff visited Alice at regular intervals and told me that they were concerned to ensure that there should be someone with Alice at the moment of her death but there would not have been a carer consistently present during this period. Again this is discussed in the next chapter.

Alice was separated from the other residents, some of whom were close friends, not just by keeping her in bed and in the private space of her bedroom, but also, by the lack of access that was afforded to those residents who had become her friends. This is an issue that I return to in Chapter 6 when I describe the last day of Alice's life. As I argued earlier, the empty space where Alice usually sat became an absence that served to mark her 'dying' to other residents. During my fieldwork and when Alice was 'living', she had been the focus of their attention and I was struck by how Alice's chair in the lounge remained a powerful symbol and reminder of absence from her 'living' space. Each time I passed through the lounge I noted how the remaining residents continued to sit in their usual place, around Alice's empty chair.

In the next vignette, the status of 'dying' is attributed to a resident called Elsie who had suffered a stroke.

### **5.5.2 Vignette 2: Elsie 'dying' in St Mary's House**

#### *Setting the scene*

St Mary's House was a large Roman Catholic residential home in the North West of England, which housed 70 residents. It was both a residential home and a convent, situated in extensive grounds at the bottom of a long drive. The home was once an orphanage and over the years, and, as a result of changing demography, it had become a residential home for older people. There were other similar homes world-wide, however, the decline in women taking religious orders in the UK meant that there were only three remaining nuns working in St Mary's House; although there were retired nuns living in the convent and a nun and a priest in need of more extensive care among the residents. This spacious home had a chapel attached to it and this is where most of the residents attended mass once or twice a day. The chapel was also open to the public and a full service was held every Sunday; members of the public also attended on weekdays. During the period of time that I was in the home, a new lift was being installed, and, in

one of the dayrooms in the home, a sister and a priest held a service for those residents who were not able to manage the stairs. The residents who were confined to bed received the sacrament of the sick.

St Mary's House was divided into three units – one on each floor. During the day, each unit had its own regular three or four members of staff. At night an extra staff member offered support to each individual member of staff in charge of each floor. In the extract that follows I describe how Elsie was thought to be 'dying'.

### **Fieldnotes: St. Mary's House**

On Thursday, I arrived at St Mary's House just after lunch and went upstairs to the second floor. Carole, a care assistant came to meet me and told me that Elsie was dying. I joined the four staff members on their break and they complained to me about the consequences of being short of staff when someone was 'dying', *There's not enough staff on duty to allow someone to sit with Elsie*. I explored with them the issue of sitting with residents who were thought to be dying. I asked, *I've been told by Sister Margaret that death is a special event here, is that why someone would sit with a dying resident?* (Sister Margaret had told me that the moment of death was highly significant and should be witnessed by as many people as possible.)

One carer replied, *Hah, they're not living in the real world, the nuns; they don't have to cope with what we do. They have no worries*. Another carer added, *They're protected and they expect everyone to be the same*.

[When I reflected on this I felt shocked by their response. I had expected the staff to be more in sympathy with the religious and spiritual ethos of the home.]

The staff who were silent nodded in agreement as they ate their toast.

Carole remained quiet and kept her eyes down.



I asked, [addressing my question to everyone there], *What do you think is the reality, then?*

The same carer spoke, *You have to get hard, you do, you have to get hard. Because, erm, when you first come here, you are close to the residents, but they leave you [pause] they die and there is no point in staying close to them.*

I asked, *Is this a way of avoiding pain then?*

Another carer replied, this time, *No! It's more about getting used to death and dying and getting hardened by it.*

All the other carers nodded in agreement to this.

In this extract from my fieldnotes the views of the staff were similar to accounts that I would hear later. Not everyone that I spoke to agreed about getting 'hard', but there was a sense in which the staff had to find a strategy with which to cope with loss. I thought that the staff were telling me that they were expected to be both close to the residents and also able to cope. This suggests that, by being able to separate out 'living' and 'dying' into different spaces of the home, staff were also managing the emotional boundary between the experience of loss and bereavement and being professional – or avoiding emotional pain.

There seemed to be a lot of focus on the difficulty that Elsie's 'dying' placed on the staff. This contrasts with Regis Home, where the staff showed more concern for Alice, even though there was not anyone available to sit with either resident. Despite the differences in what staff in both homes expressed about their feelings towards each of the residents, the privileges that the status of 'dying' conferred on Alice and Elsie was expressed as a burden by the home staff.

### Fieldnotes: Meeting Elsie

People began to leave the staff room and Carole offered to take me to meet Elsie. She told me how individual care staff members become key workers to certain residents, and, while on each shift they looked after all of the residents on that floor, they got to know 'their own' residents and got to know when they were not well. This meant that the key worker was the person who got to know 'best' if 'their' resident was 'not well'. At this point, we were outside Elsie's bedroom door, which was ajar.

I asked Carole to tell me the sort of thing she meant by that and she explained, *Well with Elsie, for instance, she's gone off her food and she's not drinking much now. When someone is dying, the nose changes shape and then the face sags and becomes indented here.* (She pointed to her own cheeks).

In this extract Carole used the loss of interest in food and drink as clear markers of 'dying'. She also added her own signs of facial change to these more traditional markers. For her this was a universal sign of 'dying' but interpreted as part of her own experience, and not necessarily shared with other care staff in St. Mary's House.

### Fieldnotes: Elsie's care

We then entered Elsie's room. She looked very pale and was sleeping. Carole handed me the chart at the bottom of her bed. She told me that the care for Elsie was *more intensive and included, two-hourly turns, fluids etc and sitting with her or visiting on a regular basis.* On the chart was written '2 pm: Turned and sips of water taken.' I looked at previous entries and they were similar and consisted of a one-line comment that referred to what had been done to Elsie with no comment about her condition.

Later that afternoon I noted that no one was sitting with Elsie. I walked along the corridor to the staff area where two staff members were folding linen. I wondered why the linen should take priority over sitting with Elsie. I asked how often the linen came up to this floor and one carer told me that this was the first task of the afternoon on every weekday – after the residents had been settled.

For the home staff the care that was given to Elsie was completely different to the routine care given to 'living' residents. Carole called this type of care 'more intensive'; however, no reference was made to Elsie's condition in the brief written notes that were made by staff in the report. It was as if care was given to Elsie because she had been categorised as 'dying', regardless of what might be happening to her. This was similar to the way that rehabilitation was produced in care homes, which I discussed in Chapter 4. The overarching and dominant routine of providing a particular type of care seemed to have been triggered by the change in Elsie's condition and her subsequent transition into 'dying'. I would argue that this status passage (van Gennep, 1960), rather than the specifics of Elsie's individual needs, triggered a different routine of care that had replaced the previous 'living' care.

#### **Fieldnotes: Handover**

The next morning I joined the staff for the handover meeting, to hear what the night staff had to say about Elsie. All of the staff members smoked during the meeting.

Elsie was discussed first at the handover: *Elsie is still very poorly. We've tried to pop in and see her when we can and Sister Margaret came and did her a care plan. We've just turned her and done her mouth. There's been a slight improvement this morning.*

At the end of the report, Carole and I left this meeting and visited Elsie together. She looked better to me than she did yesterday and was sitting up in bed. Carole told me that, *She is too bright, if you get my drift.*

In this brief extract, despite the noted improvement in Elsie's condition, Carole continued to interpret all signs as being part of the evidence for Elsie's imminent death. Rather than 'brightness' being a sign of improvement, as traditionally it would be interpreted, Carole considered Elsie to be 'too' bright. It was as if Carole was telling me that she was not fooled by this 'false' sign. She was also suggesting that Elsie was aware of her imminent death and might be in some way resisting 'dying', by trying too hard.

### *Summary of fieldnotes*

When I returned to the home two days later, Elsie had made what Margaret called a 'dramatic' improvement, and was sitting out of bed. Despite the signs that Elsie might recover, some staff members seemed to think that she might still die. For example, Carole and Marion told me that Elsie had *seen someone* and was *talking to someone*. Carole then explained to me that Elsie *is not sleeping and is afraid to close her eyes*. I asked Carole to explain and she replied, *She is afraid to let go, in case (...). I believe in this, it's a sign*. I then asked her what it was a sign of and she replied, *Someone has come for her*.

Yesterday had been Carole's day off and she told me that she had phoned in to see how Elsie was. She also told me that Elsie's key worker, Terry, was on holiday and would be very upset if he came back and Elsie had died. Carole told me, *Elsie doesn't have any family to sit with her*. Some of the other home residents visited Elsie during the morning. Two of them said the rosary with her. Carole confided in me that she was worried about not being a Catholic, because she did not think she was qualified to cater for Elsie's religious needs, and that there was no Catholic sister on this floor to do so.

During the week in which Elsie was thought to be dying, I talked to all the staff members who were involved in her care, Carole, Marion and Roberta – as well as the head of home Sister Margaret, who set up the care plan and oversaw Elsie's care. The care assistants all told me that they found caring for her 'stressful'. The staff who were not directly caring for Elsie, but who were affected by the increased workload, expressed resentment that there were not enough staff to be with someone who was 'dying', especially at night. The night nurse told the day staff in her verbal report five days after Elsie was first diagnosed as 'dying', *'Elsie has slept well. She is much better this morning. I think she's out of the woods.'*

#### **Fieldnotes: St. Mary's House**

After the report, I talked to Carole and asked her what she thought of Elsie's improvement. She told me, *Her nose is still changing and I don't think she will recover from this turn. Don't get me wrong, I want her to get better, but I don't think she will.*

She asked me to help her to put Elsie back into bed. She had been sitting out for an hour. Carole told Elsie, *We're just going put you into bed, my love.*

Elsie's paralysed side was much contracted. I felt concerned that we might hurt her. As we lifted her, Elsie screamed out. I looked at Carole with concern. She responded, *She has been given pain killing tablets, but they don't work when she is moved. The GPs don't care, you know, because the residents are old.*

I heard Elsie's chest 'rattling' when we moved her. Carole whispered to me, *It's a death rattle.*

I asked Carole's permission to look at the report book, in which comments about the residents that were considered to be worthy of noting were recorded. Since the day that Elsie was diagnosed as 'dying',

she has been the first name on the list and her condition had been recorded as 'gradually improving'.

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The concern about the pain that Elsie suffered on movement contrasts with the interpretation that was given to me for Alice's pain at Regis House. Despite the view that Elsie's condition was improving, Carole did not seem to be convinced and noted the change in Elsie's nose – which was more pinched, and the sound of phlegm rattling on her chest, which she interpreted as the death rattle. Later when I talked to Sister Theresa, she told me that Elsie was *'on the mend. She was a bit dodgy the other night and I thought we might lose her, but she's rallied, hasn't she?'* I talked to Roberta, the senior carer on this floor. She had called the doctor to see Elsie, to see if he thought she would recover and to make sure 'she is on the mend'. I asked Roberta if I could talk to Doctor Riley and she was happy for me to approach him and ask him myself when he came. She promised to tell me when he arrived. Two hours later Roberta told me that Dr. Riley was with Elsie and was willing to spend a few minutes with me after he had seen her.

#### **Fieldnotes: Talking to Doctor Riley**

I waited for Dr. Riley in the small treatment room that served as an office. He joined me about ten minutes later. I asked him how long he has been associated with St Mary's House and he told me he had been a GP there for the past thirty years and that he was born just a few streets away. He added that he knew his patients very well. He also volunteered the information that he was a Roman Catholic and his mother told him that he could either become a priest or a doctor. He threw back his head and laughed and I laughed with him. I asked him what type of GP practice he had and he told me that he ran it alone with just locum cover. He did not have any partners. He was due to retire shortly and did not enjoy working

in the job anymore, 'now that it is so financially focused'. I was conscious that I had been granted just a few minutes and decided to focus on Elsie.

I asked him, *'How do you find Elsie today?'*

He told me that she was in what he considered to be *a state of dying*. He added that she had surprised everyone by pulling through on Thursday night, but *she won't recover. She may last a few more weeks, emm, but she's terminally ill. She's had a CVA<sup>4</sup> and this is the cause of her sudden deterioration last week.*

I said, *When I helped to move Elsie, I noticed that she was in a lot of pain. How will you manage her pain?* He replied, *I'll manage it the same way as any other pain and give her something when the end is in sight.* I asked, *Like?* He replied, *Morphine, the usual thing. She's not ready for that, yet.*

I wanted to challenge this comment, and ask what you had to do to be ready for good pain relief, but Dr. Riley lifted his case and opened the door. I shook his hand and thanked him and he told me *it is a pleasure* and he hoped my research went well, *because no one cares much for older people any more,* He added, *Except here, the sisters do a grand job, here.*

As stated earlier, the title of this chapter is based on phrase that Dr. Riley used in this extract. The term 'a state of dying' suggests certainty about the diagnosis and a place

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<sup>4</sup> CVA – Cerebro-vascular accident, refers to either a clot in the brain which deprives a large area of brain tissue of oxygen and causes this to die, or a bleed which can have the same effect. Both types of CVA are more commonly called a stroke and result in a one-sided paralysis and depending on the site of the cerebral event, a loss of speech.

where this is located. I gained the impression that while it was possible to fluctuate and make small improvements, there was no way back to the state of 'living' for Elsie. Dr. Riley's diagnosis and his opinion had cast her into this state. The fact that Elsie had suffered a stroke served as a medical marker for the end of her life; and this served as her passport into the 'state of dying'. However, reserving Morphine until the 'end was in sight', suggested that Dr. Riley did not consider Elsie's death to be imminent. I did not ask him over what period of time Morphine would be used, but practice in other homes was that it was only administered in the last few days or hours of someone's life.

Elsie did not die during the period in which I was in the home. On a subsequent visit a month later, Sister Margaret told me that Elsie had died and that, *'in the end it was quite quick, you know.'*

## **5.6 The status of dying and terminal care**

Glaser and Strauss (1976) highlight the importance of being able to make temporal predictions of death for those people who work in the area of death and dying. They claim that this is explained by the need to reduce the uncertainty associated with death and thus 'temporal predictions of dying trajectories' enabled staff to prepare for death and, in care homes, this included the expressed aim of affording residents the benefit of terminal care. Senior home staff, with experience of death and dying, were more likely to be able to assess whether or not a resident was 'dying' and, if so, how imminent the death might be. However, while staff often speculated about the significance of particular signs of 'dying', this 'dying' status had to be confirmed, or conferred onto specific residents by a doctor, most often the resident's GP, as the vignettes illustrate, although some residents received a diagnosis from other doctors. I have argued that doctors as imprimaturs would formalise the period of 'dying' and also decide whether or not to launch a rescue for those residents whose lives were considered to be worthy or capable of being 'saved'. General practitioners might also decide to transfer residents if it was



agreed that it was beyond the home's capacity to care for them in this 'terminal' phase. Therefore, despite the fact that it was usually the resident's general practitioner who made any formal diagnosis of 'dying', the senior staff members were the people who orchestrated the management of 'death and dying'. As in the vignettes, a senior staff member or head of home would summon a doctor and request his or her opinion; and, once confirmed, would draw up a plan for terminal care and notify any close family members. In the vignettes above Elsie had no family to contact. Alice's nephew had been summoned just hours before she died. Not only did heads of homes manage the disclosure of information about a resident's condition to relatives, they also made decisions about how much information should be given to other home residents. I have shown that when Alice was thought to be 'dying', the senior staff nurse and matron kept informed those residents who had shared the same lounge with her. 'She is so poorly'; matron told residents the day before Alice died. However, at no time were the residents told that Alice was 'dying'. It wasn't until Martha, a close friend of Alice and fellow resident, went to visit her that she saw Alice was close to death. Martha told me later that she had prayed to God that Alice would be spared.

The privileged status of 'dying' afforded a routine of care that was distinct from other forms of care. By setting up a routine of terminal care, usually through a care plan, staff differentiated 'dying' care from that given to 'living' residents. This involved residents being nursed in the private space of their own bedroom and no longer sharing the communal spaces of the home. Therefore, the absence of 'dying' residents from public spaces not only separated 'dying' from 'living' residents, but also signalled to those residents who were 'living' what was taking place.

But if the status of 'dying' was one of privilege, what were the material benefits which that status bestowed? The rhetoric of a 'good' death, as discussed in Chapter 2, was not always the reality. My observations revealed that the main focus of end-of-life care was on the physical needs of residents. In particular, keeping residents clean and

free from pressure sores was the main aspect of this care. Staff expressed the aim of avoiding a 'lonely' death by sitting with 'dying' residents, but this seemed to be compromised by staff shortages and different priorities. If relatives were not available to keep a bedside vigil, then staff would visit a 'dying' resident at regular intervals. For example, matron set up a care plan for Alice, who was 'dying' over a period of two days that included the need to change Alice's position every two hours to avoid pressure sores and to offer her liquids. The staff visited at least every hour, and when the two-hourly care was due, they spent longer with Alice, sometimes up to ten minutes, performing the tasks of physical care-giving.

## **5.7 Conclusion**

In this chapter, I have argued that there were several key reasons for the need to predict death. Predictions were based on markers and these did not serve as independent markers, but were individualised in that each resident's production of 'living' provided the base from which an assessment of significant changes were marked. While these diverse signs shared common features in terms of being 'non-living', as signs of 'dying' they were also subject to variations in interpretation. The first part of the chapter focussed on common markers of 'dying', such as not eating and drinking and medical conditions, including stroke and pneumonia. These markers were taken from retrospective accounts of death. Making predictions was more complex and I used vignettes to illustrate the context and complexity that was involved in making such predictions about death.

It might be the case that care staff had the power to decide who should be entitled to terminal care by instigating a care plan. This action usually needed to be sanctioned by a GP, who would offer a medical opinion about whether or not a resident was 'dying'. It was also the GP who maintained the professional power to prescribe pain relief. It was not just care staff who interpreted signs of 'dying', residents and relatives also participated in making predictions of 'death and dying' and interpreted signs. Once

the status of 'dying' had been awarded, it was the role of any surviving relatives(s) and friend(s) to change their pattern of visiting and, if possible, to sit at the bedside to perform a death-bed vigil, as the next chapter shows. Therefore, once 'dying' was sanctioned by a change of care routines, including a withdrawal to the private space of the bedroom, relatives performed a different role from that of visiting their 'living' relative or friend. Likewise, other residents, regardless of their relationship with 'dying' resident, were expected to continue to perform the acts of 'living'. These routines were sometimes performed around the 'dying' space created by the absence of a resident within the 'living' territory of the care home. However, this empty space had to be coped with in ways that did not disrupt 'living' patterns. At one extreme demonstration of 'living', the staff of St Mary's House continued to fold linen, while Elsie was alone in her room. For them, death was the reality of life and not a special case, albeit one which they did not want to confront. Conversely, Martha sat beside Alice's empty chair wringing her hands in distress and praying for her friend to 'be spared'.

I argue that, not just care home staff, but also residents and their visitors made predictions about death and for a diverse range of reasons. I have also argued that, for home staff, the premium on being able to recognise 'dying' was partly derived from the need to provide the quality of care that could ensure a 'good death'. The activities that I saw following the diagnosis of 'dying', suggested to me that making a distinction between 'living' and 'dying' served other purposes, among which, was the need to keep 'death' at a distance from 'living' residents. In this thesis, I argue that the point at which 'living' and 'dying' threatened to meet heralded a dilemma that made greater demands on staff performance around the 'living/dying' older body. However, the reality of old and extreme old age, particularly for those people who lived in care homes, was that death was more likely to be imminent. My observations revealed the extent to which these boundaries (Douglas, 1984) between life and death were maintained and the strategies that staff deployed in order to do so. Together with this, and with the emphasis on 'living', it is not

surprising that for older people in homes the dying trajectory was interpreted very narrowly as a few weeks or days before death.

While I have argued that the categories of 'living' and 'dying' served several functions, it was also significant that the strategies that surrounded the categorisation of 'living' and 'dying' needed to be sufficiently flexible to allow for any forms of resistance that 'dying' residents offered up. For example, while there was discussion around the extent to which Elsie was 'improving', any attempts that she made to return to 'living' were discredited. Carole and Dr. Riley were determined that Elsie was 'dying' and continued to maintain that categorisation; choosing to interpret all of Elsie's behaviour into evidence of 'dying' despite the resistance that these offered up.

I would argue that, in a spiral of gradual but highly uneven decline, which was the case for many older and frail residents, the boundary between 'living' and 'dying' was not easily demarcated and, therefore, predictions were difficult to make. Keeping death concealed as part of the focus on life resulted in seemingly inherent 'contradictory' performances around 'dying' and 'living' residents. Furthermore, I argue that separating 'dying' residents from those who were 'living' was problematic in settings where death was viewed as the 'natural and timely' outcome of a long life. It would appear that one of the strategies to cope with this ambiguity, and the blurred boundary was to keep 'living' and 'dying' residents physically apart, not into 'dying' spaces, but into the private spaces of the home; usually the resident's bedroom transformed into a sick room. This helped to explain why it was that once a resident has crossed the 'living' and 'dying' boundary, it was difficult for them to return and, instead, he or she was suspended, either in a 'state of dying' over a longer period than anticipated, or else, like Grace in Seaview House (see Chapter 4) in a liminal space between 'living' and 'dying'.

## CHAPTER 6

### Anticipated death in care homes

#### 6.1 Introduction

In this chapter I discuss the terminal period of dying and return to the concept of a 'good death' to consider which features made death in a care home 'good'. I then use two vignettes to show how death-bed scenes were enacted. The first is the death of Alice in Regis House and is a continuation from the previous chapter in which I discussed what happened when Alice was diagnosed as 'dying'. This death was interpreted by the home staff as a 'good death'. The second vignette is that of James whose death was more problematic. The care staff at Autumn Lodge, in which James died, felt unable to provide terminal care and tried to get him transferred to hospital. This account reflects the ambiguity that staff experienced about his death.

These two deaths that I observed directly during my field work, contrast in several ways. Most significantly, the death of Alice was one which was constructed as 'good' and that of James as 'difficult' and 'out of place' (Douglas, 1984). While both Alice and James had lived in each home for a reasonably long period of time, their identity and the role which each played within the home was different. For example, I describe how James could be considered to have suffered a partial social death (Sudnow, 1967) and as a consequence, how his death seemed to have little impact upon the home; while Alice was someone who played a key role in the social life of the home, and consequently, her death had a major impact on staff and residents' emotions. Another contrasting feature of

each home was that Regis House had a 'home for life' policy, which meant that the staff were happy to provide terminal care and, as far as possible, to enable Alice to achieve what they considered to be a 'good' death. The staff in Autumn Lodge expressed ambiguous feelings about caring for James when he was 'dying' and showed reluctance to provide terminal care for him.

In this chapter I also consider what happened at the moment of death and immediately afterwards. The way that the bodies of Alice and James were handled after death, reflected many of the accounts that I heard from staff about the status of dead bodies. I describe how the body of a resident was transformed from a deceased person into a corpse and how the deceased resident then became an object and something to be feared.

Throughout the chapter I draw upon the theories of Goffman (1968) to explore the performance of death in care homes for older people. I develop my critique of this work via an engagement with the data. For example, my exploration of what happened at the time of death meant that I needed to consider the relationship between ritual and emotion. While Mary Douglas' (1984) concept of the body as potentially dirty and dangerous was also useful, questions remained about a disjunction between shared reactions to dead bodies, particularly the perceptions that staff had about residents' attitudes to the status of the dead body. These staff attitudes and their perceptions of the other residents' attitudes to the corpse, served to sustain the corpse as an object to be feared.

## **6.2 Setting the scene for death in care homes**

As I discussed in Chapter 4, death and dying in care homes was more likely to be constructed as a natural and timely event in settings where older people occupied a space between natural and medicalised death (Komaromy and Hockey, 2001). Increasingly, older and frailer 'living' residents, separated from society, experience what Sudnow

(1967) would call a social death. Despite this, residents were encouraged to look upon the home as their own and expected to take part in the rehabilitative activities of 'living'. I also argued in Chapter 4 that, while homes for older people were both public and private spaces, within the home, the separation of 'dying' residents from 'living' ones formed part of the routine of terminal care.

When 'dying' residents spent an unusual amount of time in their room, other residents who previously had shared the same public space with them noted their absence. Therefore, as part of the production of 'dying' this absence needed some explanation, which had to be provided by the person in charge of the home, or senior staff. My observations revealed that it was rare for staff to tell other residents that someone was 'dying' and, instead, would use a range of euphemisms, most commonly 'not very well', 'poorly' and 'failing'. However, in contrast to the concealed nature of 'dying', death was orchestrated as a significant event which occurred over a short period of time, usually days or weeks. This sets the scene for the production of a 'good death' which I discuss next.

### **6.3 The 'good death'**

In Chapter 2, I explored the concept of a 'good death' and argued how its interpretation depends upon context, at the individual, institutional and social level (Komaromy, 2004b). All of these levels comprise a set of dimensions which are framed by wider levels, and yet, are in a dynamic relationship with each other. For example, at the level of individual interaction, past, present and future experience would affect the way that people interpret what a 'good death' might mean to them. This would also be affected by the perceptions of their carers. Given the difficulty of achieving an agreement about what this meant, the institutional care setting affected what it was possible for people to achieve. Finally, the social, ethical, political, economic and legal structures that exist in society impacted upon the extent to which a 'good death' could be achieved. All of these factors

were in a dynamic relationship and it was not surprising that, even if it was possible to agree what a 'good death' might mean, and for whom this was good, there is no straightforward way of enabling this to take place.

From the interviews in the commissioned study (Sidell *et al.*, 1997) heads of home were remarkably consistent in their views about what they considered to be a well-managed death. These included most commonly, enabling residents to die in what had become 'their' home; not being alone at the time of death; being pain free and receiving good physical care. Most of them wanted to enable dying residents to achieve a 'good death'; summarised in the words of one head of home thus:

*Peaceful, pain-free and in familiar surroundings' (ideally in what had become their home).*

Another head of home stated:

*It is our way of showing them that we care. It is also important to other residents that they see that they will be cared for when their turn comes.*

Residents who talked to me about how they wanted to die were more likely to focus on what happened after death. However, this does not mean that they were not concerned about the period of 'dying', since many expressed a concern *not to suffer*.

When the notion of 'good death' is impossible to define, varying as it does between every individual and, in this thesis, between homes and those who have the power to provide care to 'dying' residents, it made the way that 'dying' was produced problematic. For example, I have discussed how, while senior home care staff managed the production of 'natural' and 'timely' deaths, the final say on what had occurred was left to medical staff who had the power to define both 'dying and death'.

I explore next the way that the notion of a 'good death' was affected by this general context of home life and was also subject to a wide range of factors. The



nuanced accounts in the vignettes of two residents' deaths beg questions about the extent to which they were 'good'.

### **6.3.1 'Good death' as a significant event**

Here I argue that there were many practical reasons to explain why it suited home staff to define the period of 'dying' quite narrowly. It is also the case that by doing so, it was difficult to do much more than attend to quite basic physical needs.

All of the focus on days or weeks at the end of the life of a resident placed a high premium on the care that was given in this period. I argue that the performance at the time of death might have served several purposes. First, the performance of terminal care provided staff with the means by which to manage the tensions around the boundaries between life and death. This was because, despite the emphasis on 'living', the day-to-day reality for care staff was one of the constant 'management' of the slowly disintegrating bodies of residents who were washed, cleaned, fed and presented as 'living'. Having a distinct form of care for 'dying' residents enabled this boundary to be better maintained. Second, it seemed to be likely that providing more intense care near the end of life conferred significance upon a life, when that significance had been eroded or lost. By foregrounding death-bed scenes as performances, I inevitably drew upon the ideas of Goffman (1990). The dramaturgy in which care staff, visitors, dying and surviving residents presented themselves in everyday life was dependent upon convincing the 'audience' that their actions were authentic. Senior care staff directed the drama and 'caring' relatives who kept a bedside vigil were significant actors in this drama. The successful outcome of a 'good death' required that everyone should be convinced of the performance.

Furthermore, Goffman (1968) described the regulation of people in 'total institutions', in which there are restrictions and deprivations, in a way that contributed to my understanding of how deaths in the institutional territories of care homes could be

produced as both significant and timely and natural events, and how staff were able to produce such 'good' deaths. It seemed clear that the event of death was one that needed to be carefully managed. There were remarkable similarities between death-bed scenes and the theatrical performance which Goffman (1990) calls a 'dramaturgy'. My earlier points in Chapter 4 suggest that the pendulum might have swung too far, in that the focus on living seems to have overshadowed death and dying. The loss of 'self' which older people suffered contributed to the need to give more meaning to life through death-bed rituals. Thus, experienced staff needed to manage the end stage of 'dying' so that it did not appear to be discrepant with the notion of a 'natural' death and thus threaten the boundary between life and death. Furthermore, Goffman (1990) would argue that home staff might not need to realise the moral standards, in this case of being both the surrogate family member and the professional, rather they needed to give a convincing impression of this realisation. However, I will argue later that the role which people occupied was not a fixed, embodied one and it was possible for people to occupy different roles at different times.

This placed a demand for staff to predict the final phase of 'dying' and how this was predicted is the focus of the next section.

### **6.3.2 Staff Predictions of the terminal phase of 'dying' as part of achieving a 'good death'**

Even when residents were ascribed the status of 'dying' and were in receipt of terminal care, home staff wanted to be able to predict the time of death more precisely. Therefore, following a diagnosis of 'dying', staff continued to read signs on the body of any 'dying' resident that might herald the *proximity* of death. For example, Ann, a night nurse in St. Mary's House, explained to me what she considered to be a significant change indicating that a resident, Eve, was nearing death.

*Eve is talking about her husband today and he died some years ago. She has never mentioned him before.*

In contrast to the individualised markers of the beginning of trajectories and Ann's illustration above, a senior nurse in Church House elaborated on how she predicted the proximity of residents' deaths by using her own method. I noted the extent to which she suggested that it was possible to generalise this sign to all 'dying' residents. In other words, she used this as a universal marker because, although it was something that she based on her own experience, as the following quote shows, she generalised this marker to other 'dying' residents:

*I think sometimes they tend to lose a spark. You do know that there is a change, whether we would link it with them knowing, or us knowing that they might be near to death, I'm not sure, but they lose a certain spark about them, don't they?*

It was not only staff and relatives who needed to be prepared for death; another closely associated feature of good death was that 'dying' residents should also be 'ready' and 'resigned' to death. Some staff members told me that this state of readiness or acceptance of death, depended upon the resident's faith. As one head of home put it:

*I find that people who have more of a simple faith, no matter what their beliefs are, tend to have an easier time.*

Staff also recounted stories of distressing periods of 'dying', which were peacefully resolved. The following account of Herbert's death from the staff nurse of Victoria Home highlights a resolution which was thought to have been achieved. She said:

*He was really agitated all day – the previous day that is – and we were worried that he was in pain, but he calmed down at night and died peacefully a few hours later.*

This example of a resignation to death illustrates part of the wider construction of death in old age as 'natural' and 'timely'. The need for the resident to be resigned to death was

an important aspect of the staff being able to orchestrate a peaceful death as part of a 'good death', since residents who fought death threatened the ideal, 'peaceful' death. This made it surprising to me that many staff members told me that they did not see it as their role to introduce the subject of death to residents who were 'dying'. An exception to this was St. Mary's House in which the spiritual preparation for death was an integral part of home care and something that was ongoing for all residents. However, there was a division of labour in this home, and it was exclusively the 'experts' in religion, such as the nuns and priests, who managed this aspect of spiritual care.

I have argued that it was usually the resident's general practitioner who made any formal diagnosis of dying, but it was the senior staff members of each home who orchestrated the management of death and dying. For example, I showed with Eve described above, and Alice in Chapter 5, that a senior staff member summoned a doctor and requested his or her opinion; and, once confirmed, drew up a plan for terminal care and notified any close family members. These senior staff were also the people who managed the disclosure of information about a resident's condition to relatives and made decisions about how much information should be given to other home residents.

### **6.3.3 Residents' views of death**

Those residents who talked to me about their own death did not predict when they might die as much as they talked about the manner of their death. For example, in St. Mary's House, the nun and priest to whom I talked, both of whom were residents in the home, told me that, whatever happened to them would be according to the 'will of God'. The priest, Father O'Connor told me that his faith was about 'not being afraid'; this he explained was because, 'my whole life is a preparation for death'. He also told me what he expected to happen after death. The next time he saw me he invited me to go and see him in his room. What he told me and his state of agitation suggested that he had not thought about death as such a potential reality before. He said:

*Ever since you came I have been thinking about your visit, and I want to say something to you. I do not think about my own death. I always think that death will happen to someone else, but it will steal upon me like a thief in the night.*

Betty had been a resident in St. Mary's Home for over 40 years, having been admitted when she was a young woman. Betty told me about how, during the years she had spent in this home, she shared her room with other residents, who had subsequently died, and how she predicted when that death might occur. In an account of the death of her roommate, Josie, Betty told me that the staff did not tell her that she was 'dying', 'They never tell you much. You see they don't make it public.' This left Betty in a position of having to work out when Josie might die. I asked her how she decided that Josie was 'dying' and she told me:

*Oh! When I saw her - I knew - because she couldn't walk. And then she went thin and bony like, you know. Her face went like that (indicating that it was drawn and thin) I thought, you look as though you've got TB. But cancer does that too. Not with everybody, mind you.*

She reported what another roommate, Fanny, had said to her about the home's custom of keeping a deathbed vigil:

*'Oh', she says, 'I hope they don't come and stare at me like that, when I'm going. Make you think they want to hurry you off. As though they want rid of you quick. You're lasting too long'. That's what one old lady, Fanny thought. Made me think, I'm lasting too long to have a slow end like that.*

Another resident of St. Mary's House, Nora, told me that she had recently converted to Catholicism and how this meant that she no longer had any fears about death. She also told me that she was delighted to be in St. Mary's House for the end of her life. However, Mary expressed some anxiety about the process of 'dying':

*I want to die in the home and I hope that the Lord makes it easy for me.*

From my field work data, I also found that relatives made predictions about death and it is these that I turn to next.

#### **6.3.4 One relative's view of death - Taking too long to die**

Relatives told me about the quality of the 'dying' period. For example, I interviewed Joan at home six weeks after her father's death. In her account she described how she wanted him to die sooner:

*He was beginning to become unconscious, even though his heart beat was very strong and I really wanted him to die. I didn't want him to suffer any more because there were indignities, even though he was in St. Mary's House. He had to be changed like a baby and I didn't want that to go on. He was eighty-seven and my mother had gone very peacefully. I had seen my mother going peacefully and I wanted him to go peacefully, but he didn't. It was a long drawn-out illness.*

Later she expressed the loss she experienced when her father stopped singing:

*His singing was good, and when he lost his voice, he couldn't sing any more and I thought I would never hear him sing anymore.*

When I asked Joan if she thought that her father knew that he was 'dying', she seemed to interpret this as her father's wish for the manner of his own death and told me:

*My dad had a very happy life and he didn't want to die. He didn't seem to be afraid, I don't think. One time after his first stroke, he told me about a sect in North America where they just fall asleep.*

For Joan her father's drawn-out death was undesirable which suggested that the ideal period of 'dying' had an optimum time frame. Her view supports much of the data that I collected and reflects accounts given by other residents and relatives. This suggests that the need for care staff to restrict the terminal stages of care was not confined to the practical abilities of the care home staff. In her study of hospice care, Lawton (2000)

argued that by living beyond their predicted time of death, people dying with cancer could 'live too long'. The argument put forward by Joan above and Betty, about her friend Josie, in the previous section suggest that once the death-bed vigil had been set up, then the dying person should 'get on with it' so as not to keep the staff and relatives waiting too long.

## **6.4 Terminal care routines**

Since the privileged status of 'dying' afforded a routine of care that was distinct from other forms of care, by setting up a terminal-care routine usually as a written care plan, staff formally differentiated 'dying' care from that given to 'living' residents. As I showed in Chapter 5, this involved residents being nursed in the private space of their own bedroom and no longer sharing the communal spaces of the home. But if the status of 'dying' was one of privilege, what were the material benefits which that status bestowed? My data show that the rhetoric of a 'good death' was not always the practice reality and revealed that in most of the homes the main focus of end-of-life care was on the physical needs of residents. In particular, keeping residents clean and free from pressure sores was the main aspect of this care, more so than adequate pain relief. Staff expressed the aim of avoiding a 'lonely' death by sitting with 'dying' residents, but this vigil seemed to be compromised by their claims of staff shortages and different priorities.

Apart from the gap between rhetoric and practice, there was a tension between the views of death in general as a 'natural and timely' event and the impact of individual deaths on the care staff. By this I mean that care staff had to manage the difficult task of not only, producing 'death and dying' as a 'normal' and 'good' event, but also, one which carried individual significance. What I noted was that there were institutional devices which helped staff to manage this dualistic role of treating death as a significant event and also behaving in a professional manner and treating death as 'natural'. It was clear from observations and talking to home staff that from his or her position of power, the

head of home directed these 'scenes of death'. Indeed, there was a distinct hierarchy and division of labour in all homes, and junior staff were not expected to have to make decisions about the care that was given to 'dying' residents around the time of death. Instead, as with the orchestration of 'dying' care, the duty fell to the more senior staff members who had professional expertise of death and dying, if not direct experience; for some senior staff members had not witnessed a death in their career.

In the next section I draw on data taken from direct observations that I made of the terminal phase of dying and the event of death.

## **6.5 The performance of the hour of death**

I have chosen the following accounts of death because, not only did I observe them directly but also, as stated earlier, they show clear differences in terms of how they were produced. Alice's death was largely scripted as a 'good death'; fulfilling the criteria described above. On the other hand, James' death was subject to staff disagreement and tensions that produced his death as 'unwanted and 'out-of-place'. The person in charge of this home, who was the deputy head of home, did not consider that it was appropriate for residents to die in the home and preferred instead that they should be transferred to hospital to receive what he called, 'proper terminal care'. The head of home, who was away at the time, was in the process of trying to change practice to one in which the staff provided terminal care, rather than transferring residents out of the home once 'dying' was diagnosed.

### **6.5.1 Alice's death – performing a 'good death'**

This account of Alice's death comprises both summarised notes and fieldnotes from my observations. I had been doing participant observation in Regis House for just over four weeks. The account that follows is a continuation of that which I have described in Chapter 5 and involves Alice's final stage of 'dying'.



### Fieldnotes: Regis Home

When I arrived (the next day) at 7.30 am I was told by the night nurse in charge of the home that there had been a slow deterioration during the night and, when I visited her, I noticed Alice's breathing was more laboured.

The care assistant was just leaving the room and she told me Alice had a 'death rattle'. Although Alice was less responsive than the day before, at times, she appeared very agitated. At 9 am two care assistants came into the room to turn her to the other side. Alice screamed out when she was moved, as she had done the day before. I showed concern and asked the staff what they thought her screams meant. One told me Alice was 'more peaceful'. I asked if she thought that Alice was in pain, and was told that the staff nurse would come soon to give her some Oramorph (liquid Morphine).

Matron had changed Alice's care plan that was placed on her locker. I read it to see if the staff were making any note of Alice's pain but it only included details of personal hygiene, including pressure area care and half-hourly fluids. It also instructed staff to: 'Observe carefully for signs of pain, or restlessness and report to trained staff'.

Secretions commonly form at the back of the throat when someone is unconscious and/or dying and is a sign of the lack of a cough reflex. By interpreting the noise that these secretions made as 'the death rattle' the care assistant seemed to be telling me that this was a further sign of Alice's deterioration and further confirmation that she was 'dying'. The interpretation of pain, as showing Alice to be 'more peaceful', puzzled and upset me. It seemed unequivocal to me that Alice was still in pain when she was moved, although her shouts were more muted than they had been the previous evening, which was not

surprising since Alice was drifting in and out of consciousness. However, this was in keeping with interpretations of behaviour that I had been given by the staff of other homes and which reinterpreted pain as other aspects of the process of 'dying' – such as resistance to death or agitation. It seemed that Alice's behaviour was being framed by the expectation of death and interpreted as part of her 'dying' trajectory. However, despite this statement about being more peaceful, the care assistant did not deny that Alice was in pain and told me that she was going to ask the staff nurse to administer Oromorph, which is an oral dose of Morphine and a strong painkiller. At mid-morning two close friends, who were mother and daughter visited. At the time, two carers were just completing Alice's care and were giving her sips of orange juice.

#### **Fieldnotes: Visiting Alice**

Alice's friends were very clearly upset and the care staff in the room appeared embarrassed and seemed to be at a loss as to what to say and do. They nodded to acknowledge the presence of these visitors but said nothing. I found the situation intolerable. I told Alice's friends who I was.

*My name is Carol and I am researching care in homes.*

They continued to stare at Alice. One of the friends, who did not take her eyes off Alice, asked, *How is she today?*

I felt the same embarrassment that the carers seemed to feel.

*She is worse today. How do you think she is?* I asked. One friend shook her head and the other said: *Oh dear, she is bad!*

I suggested that they should talk to the nurse in charge and asked them if they wanted me to find her. They said they would see her on the way out.

I offered to get them some chairs to sit beside Alice. The friend who had spoken first said: *No thank you, we won't stay. Just came to see her.*

In this scene it seemed that everyone in the room was experiencing some form of distress. I knew that it was not the formal role of the care assistants to communicate information about a dying resident's condition to visitors; indeed this was strictly forbidden. My data showed that heads of home were very clear about what information it was permissible for care staff to disclose to visitors and it was either a trained member of staff or head of home who managed the distress of any relatives. As one care assistant told me, *It's what they're paid for!* However, there seemed to be a clear expectation by Alice's friends that, because we were in the room with Alice, we would tell them what was happening. I felt upset and embarrassed that the care assistants did not acknowledge the distress of Alice's friends. In terms of the performance that was taking place at this deathbed scene, most of the actors seemed to be uncertain of what it was that they should do or say. I took it upon myself to assume the role of 'being professional' by acknowledging Alice's friends and introducing myself to them. It seemed that only those with clear roles and specific scripts as to what to say were allowed to speak, and as an outsider, I could improvise. Indeed, in the role of participant observer, I had to improvise and negotiate my role much of the time. Ultimately, however, it was left to the visitors in the scene to judge Alice's condition for themselves. On reflection, the silence of Alice's friends suggested to me that they did not see it as their right to ask for information from those care staff who were present. In this sense, they colluded, as did I, with the silence and sense of awkwardness.

The other residents in the lounge in which Alice used to sit, were in their regular chairs. This area of the lounge was close to the door which led to the corridor where Alice's bedroom was located. This afforded them a view of the traffic to Alice's room and they speculated about the events and what was happening to Alice. In this way they were keeping their own vigil.

### Fieldnotes: Friendship

Two carers came into the room and said: *Carol, why don't you have a break while we turn her?*

When I went into the lounge I could see that Alice's close friend and fellow resident, Martha, was very upset. She told me: *I didn't sleep last night, I was so upset. The Lord God will decide, but I do want Alice to recover, I will miss her so much.*

We sat together for about ten minutes in silence. Martha then said to me: *Alice told me that if I held her hand she would feel safe, so sometimes I held both her hands!*

Over the lunch break the staff continued with the normal routines of getting residents to the table and serving food. I stayed with Alice. Her breathing became deeper and more laboured. Beside Alice's bed there was a photograph of Martha. It was crumpled, as if it had been handled a lot. Then, after lunch the four members of kitchen staff all visited Alice. One of them told me, 'I'm surprised she's still alive!'

In Chapter 4, I discussed the ethical dilemma that I experienced when Alice was in pain from her leg and what I did in response to what I saw as poor pain management. Here again, I considered that if I did not intervene, it was possible that Alice's fellow residents would not have the opportunity to say goodbye to her. I was convinced that the care staff would not invite those who were close to Alice to visit her before she died. I had been impressed by the quality of the friendship between residents within the homes and the support that they gave to each other. It seemed to me, that these friends had not been offered the opportunity to be part of this deathbed vigil, because it was not seen as their right, although, in one way, they were participating in a vigil close by. Neither did the residents ask to visit Alice, nor go in to the room without permission from the staff. It could be argued that they were colluding with, or participating in the denial of being

significant contributors to the dying care of Alice. Martha told me the day before that she had nursed her sister whom she had lived with all her life:

*It was a very hard death....10 long weeks.....I was with her when she died.....I was holding her.*

Martha went on to tell me:

*God will take us all - ready or not. I'm ready because I hate being old and dependent. When he calls me I have to go. But, I prayed last night for him to spare Alice for me. I don't want her to suffer, but I want to keep her.*

I decided to intervene and asked the care staff to invite Alice's friends into her room to see her before she died.

#### **Fieldnotes: Alice's death**

At 2.00 p.m. Alice became unconscious. A very young care assistant had been assigned to 'pop in' to see Alice every 15 minutes. At 3 o'clock I asked one of the care assistants, who had popped in again, to bring in those residents who were close to Alice. At my suggestion, she brought in Martha in a wheelchair. I asked Martha if she wanted to be alone and she told me that she wanted me to stay, *please*. Martha held Alice's hand and said, *You need to really pull your socks up Alice and get better, 'cos I need you and I'm really going to miss you!* Alice seemed calmer when Martha was with her.

They spent 20 minutes together, and then, a care assistant took Martha out and brought in Dolly. She held Alice's hand and said hello, but got no response. Then, quite suddenly, Alice opened her eyes and stared really hard at Dolly. Dolly seemed pleased as if she had been acknowledged. She asked to be taken back to the dayroom. I noted she was visibly and audibly crying as she left the room. I was alone with Alice when she died

at 4 p.m. I went out to find a care assistant who called matron. Matron then came and felt Alice's neck for a carotid pulse. She nodded and immediately straightened Alice's body and then tidied the bedclothes; although she did not cover Alice's face. Matron left the room to call the doctor.

A few minutes later matron intercepted Alice's nephew to warn him of the death. Initially he was reluctant to see Alice but then decided to say good-bye.

#### **Fieldnotes: Visiting Alice after death**

I asked Alice's nephew if he wanted me to stay with him and he nodded and seemed to be relieved. He stayed for less than a minute and just stood by the bed and looked at Alice. He looked very shocked and upset and said: *I should have been prepared because I was expecting it, but this is the third death.*

I took him out of the room, and matron, who was waiting outside the bedroom, took him to her office and gave him a cup of tea which one of the care assistants had made. As I stayed with them, I noted that slowly, one by one, the care assistants on duty went to say good-bye to Alice.

#### **Fieldnotes: Certifying death**

At 5.30 pm the GP arrived to certify Alice's death. I had to be quite insistent that I should go with the GP and matron to witness this certification. The GP held a stethoscope on Alice's chest for 2 seconds and certified the death. She then sped out of the room, as quickly as she had entered, still eating a toffee and talking to matron about something unrelated to the death. Alice was not mentioned. Matron then decided to

tell the other residents who she said to me could understand and did so individually with these words: *I'm very sorry to have to tell you that on this day of the Lord at 4 o'clock Alice passed peacefully away.*

Both Dolly and Martha were very upset and crying.

Matron told me that she would lay out Alice's body on her own. She explained this was her way of saying good-bye and I did not ask if I could help. It seemed to me that I would be intruding in her private farewell to Alice. I wondered if matron was using this task as a ritualistic form of saying goodbye. It would legitimate her need to touch and hold Alice, while performing a professional task.

In the next section I provide an account of a death in a home where the staff expressed concern about having to care for a 'dying' resident and would have preferred to send him to hospital. The physical care that was provided was at least as good as that which Alice received, although it was over a shorter period of time – hours rather than days. The main difference in the account which follows is the unwanted nature of James' death in the home.

### **6.5.2 James' death – a death 'out of place'**

#### *Background to Autumn Lodge – setting the scene*

Autumn Lodge was a large residential home for older people in the West Midlands region of England. The home was divided into four units: two were situated on the ground floor and two on the first floor. The main purpose of this practice of a division into units was to create smaller communities and mitigate the institutional nature of those homes with a high population. The head of Autumn Lodge told me that this provided more opportunities for individual care and continuing relationships and was more 'homely'. The profile of residents had changed to one of increasing dependence, and a higher level of physical

care needs. Consequently, one of the units on the first floor was designated as an EMI (Elderly Mentally Infirm) unit. This housed those residents who were confused or were suffering from Alzheimer's Disease.

The account of death in Autumn Lodge features James, who was a resident in the EMI unit. James had lived in the home for four years and had developed Alzheimer's disease in the last few months of his life there. Because of this, he was transferred internally from one of the general units on the ground floor to the EMI unit. There were eleven other residents on this unit who, depending upon the staff resource, were cared for by two or three staff members during the day and one or two at night. The numbers of staff on duty could be less when staff were off sick or during holiday periods. The homes' stated policy was that of a home for life, but the staff did not have any nursing qualifications, and considered that they were not sufficiently qualified to provide terminal care. The following account of James' death highlights a tension between the institutional aim of a 'home for life' and the individual commitment of the staff. I show how, within the gap between policy and practice, the care staff in the EMI unit were highly resistant to 'doing' terminal care and verbalised this resistance. The summary below sets the scene. I had been attending the home each day for the previous four weeks, and was surprised to hear that someone was dying. Here I felt the need to be able to make predictions for the sake of the data that I wanted to collect.

#### *Summary of field notes: Thursday*

On arrival at Autumn Lodge, Philip, the deputy head of home, greeted me with the news that James, one of the residents on the EMI unit was dying. He told me that James had suffered a stroke and was semi-conscious. Philip went on to tell me that James was a 99-year-old resident who had lived in the home for four years. He told me how, over the course of that time, James had changed from someone very 'talkative and outgoing' to someone who had become increasingly 'deaf and confused'. During the last few months



James had spent increasing periods of time alone in his room. He had limited or no contact with other residents. Philip told me that he was:

*(P)ersonally very upset about this because this is not the right place for residents to die. The staff do not have the time or the skills to care for dying residents.*

I reflected that I had not met any of the residents in this part of the home yet. I felt uncomfortable about my lack of familiarity with the unit and the possibility of being perceived as insensitive and callous by wanting to make direct observations at James' deathbed. Nevertheless, I went upstairs to introduce myself to the staff and residents and to spend the evening making observations.

#### **Fieldnotes: The EMI unit**

On arrival at the EMI unit the care staff appeared pleased to see me and asked me if I was prepared to sit with James and I agreed to do so. They also told me how they did not feel able to provide *the right sort of care* for someone dying and, in particular, someone who needed fluids to be delivered via a *drip feed*. One care assistant told me that the on-call GP who had seen James that afternoon, had agreed that he needed to be hydrated and that, because of this, he should be in hospital.

This was a contentious issue within the home. I reflected that sitting with James in this 'state of limbo' seemed to be best handled by me as the stranger and outsider. It was as if James' identity had changed from that of a 'living' resident who had lived in one of the main units of the home, to that of someone with dementia who was now 'dying'. Although the staff on the EMI unit were still involved in producing residents with dementia as 'living', as with Millie in Chapter 4, the activities did not include those traditional ones of rehabilitation. The focus of care for these residents was entirely on their physical care, and, in particular, feeding them and managing any bodily leakage in the form of urine and

faeces. The following fieldnotes reveal some of the tensions around James’ place between being a ‘living’ home resident and being transferred to hospital as a ‘dying patient’.

**Fieldnotes: Meeting James**

I was shown into James’ room by one of the care assistants; James was breathing noisily and rapidly and appeared to be unconscious. His bed was pushed against the wall and there was a table beside the bed, probably to prevent him falling, (I later confirmed this with the staff).

James was lying on his left-hand side and facing the wall and I was aware of the irony of this, since Philip had told me that he thought that James had, *given up on life*.

The room was quite large and sparsely furnished. There were no signs of James’ personal possessions in the room. I was struck by the absence of connections to the outside world such as photos and personal ornaments and gifts that was a feature of residents’ rooms I saw in other homes in the study.

The staff kept a written record of the care that James received during his illness and recorded any events that they considered significant enough to record. The following excerpts from these records were written by the senior carer on duty of each shift and kept in James’ room. They contained brief comments and speculations.

**Written notes on James**

Wednesday

James appears to have had a turn. Maybe a stroke. No communication at all, just staring when awake. Slept most of the day.

Doctor’s instructions

Give liquids regularly otherwise he will have to go to hospital.

Thursday

Unable to wake James all day. GP visited and says he needs a drip, but could not get him into hospital anywhere.

P-uing OK. (passing urine).

Thursday PM

Restless and groaning, congested. Not responding.

Nowhere in this written account was there any indication that James was 'dying'. It seemed the focus of the 'problem' was that James needed fluids. On Wednesday there seemed to be a threat that, unless the care staff could get sufficient fluids into James, then he would need to go to hospital. However, all of the staff I met told me they believed that James should have been in hospital.

**Fieldnotes: Terminal care**

After just 20 minutes, two care assistants entered the room and moved the furniture and the bed away from the wall - so that each could stand on either side of the bed in order to turn James onto his right-hand side. He was now facing the open space of the room rather than the wall. The staff talked to James while they re-arranged his position. They also talked to each other about what other tasks they had to do that evening. *We're just going to turn you over now James and make you more comfortable, all right?* (This was shouted into James' ear and I noted that he did not answer).

Then to each other: *When we've done this we'll put Nelly to bed, I'll undress her while you take Rosie to the toilet.*

When they had turned James and covered him with the bedclothes again, one of them poured some warm tea from a beaker that she had brought with her into James' mouth. The tea trickled out of the other side of James' mouth onto the pillow. The younger care assistant lifted the chart from the bedside table and recorded on this fluid balance chart that James had taken 'sips of tea'. She also recorded on the same chart that they had changed James' position, and then, replaced the chart at the bottom of the bed. (I read this when they left the room). They then pushed the bed back against the wall and replaced the bedside table beside it as a barrier. The staff asked me to: *Keep an eye on him in case he rolls out of bed.*

I agreed to do this.

I reflected on the need shown by the care staff to be *seen* to be giving fluids, even though James did not swallow any. I would argue that this contradictory performance, in part, reflected a tension in James' ambiguous living/dying status. Furthermore, as long as James performed the activities of 'living', and one such activity was drinking tea, then the reality that he was 'dying' could be denied. In this illustration of 'dying' care, unlike in other homes, maintaining fluids was not part of a terminal care plan.

#### **Fieldnotes: James' death**

Throughout the afternoon shift, the same care staff turned James at half-hourly intervals and at 9 p.m. I left the room for a break. I joined two care staff, who were sitting in the residents' dining area. Rachel, one of the carers from the downstairs unit where James used to live, visited him at ten past nine. A care assistant told me that Rachel knew James well and was upset about his transfer and current illness. She added that it was

part of Rachel's routine to say goodnight to James before she went off duty.

Almost immediately, Rachel rushed out of the room in a state of distress, *He's dead, he's dead!* she told us. The other staff members also appeared shocked, and were concerned to calm her and to account for how this had happened in the space of a few minutes between James being turned and Rachel's visit. Philip was called from his office downstairs and, when he arrived, his first concern was as he said, *James' nephew 'phoned from his holiday at about 8.30 p.m. to enquire about his condition and I had told him that James' condition was stable.*

Philip had not enquired of the staff on the unit about James' condition before passing on this news, but, in any case, the care staff on the unit expected that James would live for a few more days. The care staff and Philip expressed a degree of surprise that the period of 'dying' was much shorter than they expected, and also relief that James died quickly.

The written notes for that day stated: *James passed away peacefully at 9.20 pm.*

When I visited the next day it was made clear to me that the care staff felt that it was beyond their role and capacity to care for James when he was 'dying'. The next morning I returned to the unit early.

#### **Fieldnotes: Aftermath of James' death**

I sat down with the care staff on the EMI unit as they fed breakfast to the residents. All of the residents were seated at the tables in the dining area. On one table, two members of care staff fed a resident each. I did not mention James' death because other residents were present, but, as

the staff fed the residents, one of the care staff explained to me that James should not have been in the home and that he needed specialist care and they were a residential home and unable to provide that care. Another member of staff further explained to me that she thought, providing terminal care seriously interfered with their ability to care for the living residents in the home. I asked what would have happened if I had not been there to sit with him, and one of them disclosed that she would not have *sat with James*, but would, *only have popped in every half hour to give care and to check on him.*

## 6.6 The meaning of the performance of death

Goffman (1990) argues that an important feature of any performance and the impression it creates is the authority it is given. Professional authority appeared to be an important feature of the death management acts outlined in these two deaths in that the professional 'impression' was enacted through the routines that structured how the staff behaved. However, the open resistance to completing the care in a 'home for life' of the residents in Autumn Lodge was untypical of the other homes that I observed. The death of James was untypical in the extent to which the staff declared their wish not to provide terminal care for James; even though the home had a policy to keep residents in the home to die. One of the results of the resistance in Autumn Lodge was that James' death, although viewed as being appropriate because of its timelines and because of his Alzheimer's disease, was treated as 'out of place' and therefore, did not qualify as a 'good death'. Despite the reluctance of the home to engage with end-of-life care for James, they changed the routine of care from that of 'living' to 'dying' care. As in many of the homes in which I conducted fieldwork, the plan of care for 'dying' residents was to provide physical care to the extent of keeping the resident's 'dying' body clean and free

from pressure sores, using a prescribed protocol of turning residents on a regular basis, and keeping written records of the care given. Even with a resident like James, who could be represented as someone who had suffered a 'social death' and, therefore, unlikely to have been expected to perform rehabilitative 'living', the change of care marked both a response to 'dying' and a production of 'dying'.

I would argue that in Autumn Lodge, the ambiguity between 'living' (when 'living' was like a 'living death') and 'dying out of place' produced an ambiguous performance by care staff. The care staff talked to James in raised voices as if he was capable of hearing them, while they talked to each other in normal tones, as if he could not. This represented both a formal 'professional' manner and an 'unprofessional' one during one set of activities around body care. In doing this, the staff were both 'in character' and 'out of character', and this latter could be part of what Goffman (1990) termed 'communication out of character'. Finally, the decision to have James transferred to a hospital, suggested that death needed a more 'professional' setting in which to occur.

Rachel, who had cared for James before he became confused and was very fond of him, was the person who found James dead. I would argue that, at that moment, Rachel stopped being the 'professional carer' and became instead a 'bereaved person'. For example, the other care staff provided an account to her of why James was alone at the moment of death as they would to a bereaved relative. They performed the task of justifying the unexpected nature of the moment of his death in professional terms. They did not share their shock with Rachel, even though they were also clearly shocked by the news. In this sense, being professional involved the staff in more than performance, they also had to control their emotions so that they performed the appropriate response. The form of emotional labour (Hochschild, 1983) highlights the unresolved tension between the 'real' and the 'performed' self (Goffman, 1990). The backstage discussions which home staff had with me about their feelings, and with each other while James was 'dying', did not reveal regret about not spending time with James. Indeed, both vignettes

illustrated the everyday expectation of the medical/professional appropriation of death (Hockey, 1990 and Illitch, 1977).

Lock (1996) suggests that whatever form death takes, it conjures up that 'margin between culture and nature' where mortality must be confronted. As I argued in Chapter 2, such margins are invested with power yet are potentially dangerous (Douglas, 1984) and require management in some way. Such management is 'pulled off' by an appropriate performance which at the same time serves to 'mask' or create distance from the death. The focus on the physical aspects of the 'living' body, in both performances, may serve, partly, as this mask. Yet, if, as the data suggests, death is 'matter out of place' (Douglas, 1984), the question remains as to where death has to go to be acceptable.

In contrast, Alice's death was managed as one that was 'in place' and timely, despite the home's investment in Alice reaching her 90<sup>th</sup> birthday. In Chapter 5, I described how these plans were underway and how matron had been making arrangements for several weeks. Once it was clear to the home staff that Alice was 'dying', the final stages of Alice's life were carefully scripted by matron as head of home; and, therefore, the person invested with the professional expertise and someone capable of knowing how to manage this period of 'dying'. Matron's instructions were both written and verbal. The example of the care staff, who were not allowed to speak to Alice's friends, highlighted the way that procedures pre-existed the plan of care for 'dying' residents. Alice's closest living friends were other residents in the home, and yet they did not seem to qualify as people with visiting rights during this period.

The reality of care for both James and Alice echoed the findings of the wider commissioned study (Sidell and Komaromy, 2003) in which the rhetoric of providing residents with a 'good death' was not always matched by the reality of being able to do so. For example, there were many instances when that care was cause for concern, or residents were transferred out of homes, who subsequently died. These examples of death highlight similarities and differences in the way that each home 'produced' the



death. On the surface, it might seem strange that James, whose quality of life seemed poor, was an unwanted and unwelcome 'death', while Alice's death carried regret, and yet, was produced as a 'good death'.

I argue that this data shows that Goffman's (1990) theory of 'Performativity' fails to explain the variations in these ambiguous performances around death, as a regular institutional event, and a product of the end of life in these institutions. The distancing that the performance of 'good death' fulfilled, did not satisfy the need for the staff in Autumn Lodge to cope with their emotional ambiguity and turmoil. Neither does his approach help to explain why it was that James' death seemed to be capable of creating such emotional distress.

So far, I have argued that the 'dying' bodies of the residents were produced by a process of negotiation between the practices and routines performed by the home staff, the dying residents and his or her family, and other residents. Alice's death bed scene reflected a more romanticised version of the end stage of 'dying' in which those who cared for her were able to say 'goodbye', including those for whom 'permission' had to be given. James was different, in that his social identity had been diminished by his condition of Alzheimer's' disease and his transition into death was less formally sanctioned as part of the home practice. James died alone. He created anxiety and embarrassment. It seemed that just one person in the home cared about his death. I consider next what it is that the homes produced at the end of 'dying'. In other words, after a 'good' or a 'bad death', what is left? I draw on the observational data of Alice's removal from the home to show that her dead body required a lot of attention. In the next section, I consider what happened when James and Alice died and how their bodies were treated in death. In this section, I explore the nature of death in its embodied form and how the body of the deceased resident was transformed into something that was an 'object'.

## 6.7 The status of the dead body – the production of a corpse

Anthony Synott (1993) claims that:

*In every culture the dead body is treated with respect and with ceremony; and the body remains the symbol of the self.*

*(Synott, 1993, p. 33)*

The process is also re-iterative, in that, the management of bodies affects the meanings that are given to them. The meanings that are attached to dead bodies are derived from a number of social, personal, cultural and existential sources. Indeed dead bodies not only represent death but also continue to represent the living person (Howarth, 1996). But the body after death is much more than the representation of the living person, it is a powerful symbol of different beliefs which surround death; occupying as it does the space between life and death. Therefore, the dead body represents a multiplicity of phenomena, many of which, are diverse and all of which have to be managed. How the dead are treated, particularly in institutions also reflects the treatment of 'living' inmates.

Elias (1994) helps to illuminate how the corpse has to be managed according to norms of behaviour. Turner (1987) argues that the disengagement from social life that is, in part, a result of the institutionalisation and professionalisation of illness and dying, impacts upon the social function of the dead. As I have argued above, it is these norms which enabled care staff to carry out procedures at the time of death, as part of their professional duties. The performance of last offices was carried out according to protocols, which served as a script, in which the main actors inhabited their role for the benefit of the audience, which comprised the rest of the home community. The following example from a code of practice in Peacehaven home illustrates this point.

### **Last Offices' Policy - Peacehaven**

Remove the pillows from the bed.

Straighten the body and lay it gently flat.

Leave the body for at least an hour (the hour of repose).

Make sure the body is clean, nails clean and hair combed.

So far, I have argued that the 'dying' body was read for signs of deterioration and the imminence of death. Douglas (1984) highlighted the body as potentially dangerous with the capacity for contamination, which can be interpreted on both material and symbolic levels. The death bed scenes in Regis House and in Autumn Lodge was the site of the performance of 'dying' and 'death'. After death, these residents' bedrooms were no longer where 'dying' took place, and instead became the site of their dead bodies awaiting death confirmation and disposal. If it is the case that the boundary between life and death needed to be maintained, as I argue it was, and as Hallam *et al.* (1999) argue, the dead body becomes the 'material reality of death', then its disposal would offer significant clues about its new identity. To consider this, I draw on my direct observations of what happened to Alice after her death.

#### **6.7.1 The removal of the corpse from the home**

##### **Fieldnotes: Leaving the home**

At 6.15 pm, shortly after being called, the undertakers arrived at Regis House to remove Alice's body. Matron and I went with them and on the way through the lounge to the bedroom, matron closed the curtains in the dining room, so that the residents would not see the hearse. I helped matron to move furniture around so that they could access the French doors. The room was very small and making room for the mortuary trolley

was difficult. At one point the commode that was in the room toppled over onto the dressing table and made a loud crash. I wondered how much of this noise the surviving residents were able to hear and what they thought we were doing. The undertakers took Alice's body out in a body bag on a trolley through the French doors of her bedroom unseen by other residents, who were still having tea as part of the normal routine.

When James died, the staff locked his bedroom door and told me that this was to keep his possessions safe.

**Fieldnotes: James' body**

Having straightened his body, they left it for an hour before laying it out. They had 'phoned for the undertaker to come and remove James' body much later that night; telling them that there was no rush, and that it would be better when all of the residents were in bed. I did not stay in the home to witness the removal; wanting instead to be there early the next morning to hear accounts following James' death.

I have argued elsewhere (Komaromy, 2000), that as a student nurse on a medical ward in hospital, I noticed that when a patient died surviving ward patients were not told what was happening and questions were not invited. The screens were pulled around the beds of living patients, side room doors were closed and all ambulant non-medical people were stopped and placed out of sight of the departing corpse. In order that the dead body could be moved living people were stopped. Silence descended on the ward. The concealment of the dead body, left patients and visitors listening acutely for clues. The porters waited outside the ward until a nurse signalled that it was safe to enter. The patients heard a noisy trolley whose metal status was announced by its rattling

crescendo. The sound of unresisting body hitting metal left no-one in doubt about what had transpired. The creaking closing lid confirmed the death and the sound of the chariot of death rattling down the ward served as an unmusical requiem.

After the removal of the body, the theatrical opening of the screens revealed the spectacle of an empty, bright orange mattress, signifying not a successful home discharge, but a warning of the reality that not everyone is saved and that perhaps no-one is safe. It seemed to me, this failure of medical science to produce a miracle brought shame to the staff whose main objective was to save lives. Patients and nurses colluded in the silence as the bed was made up ready for the next patient, someone who would be shielded from the fate of its last occupant.

I argue that this was a collusion, which required the key actors to resist asking questions that might have produced answers that were difficult to deal with. It was as if the formal knowledge acquired through being told something made the event real, and therefore, undeniable. On a social level individuals may suspect the 'truth', but when it is confirmed denial is impossible. This is reflected in the concealment of the sight of death. Despite all the aural information, by not seeing the corpse and not facing death, hospital staff could act as if the death did not happen.

I have also argued (Komaromy, 2000) that here are two levels of silence; that which comes from the lack of talking about an event, and that arising from a lack of acknowledgement that sounds are taking place. Also, the silence that results from a lack of discussion about death, could convey not just shame of death as a signifier of failure, but a total lack of acknowledgement of the need to recognise specific deaths as personal tragedies. If it is anxiety these practices are trying to reduce and the promotion of hope and optimism, they may not only fail to do that, but may be much more anxiety provoking and harmful. It could be argued that the concealment of the sight of death in hospital where most people expect and want people to *live* and not to die, is fully explained by

compassionate motives. But even if it could be argued that it is right to protect vulnerable people, the sounds of death and consequent imagined sights may be worse.

### **6.7.2 The unsightliness of death in residential and nursing homes**

I have argued elsewhere (Komaromy, 2000), that from my professional experience and these data findings that there was a hierarchy of unsightliness. In descending order of preferred visibility the body, contained in the coffin, was at its most dignified and eminently viewable. Here, I have drawn on the work of Howarth (1996) who makes the point that the body is rehumanised by the undertakers, through a process of numerous 'purification techniques' (1996, p. 166). Making the corpse presentable for viewing was part of the production of a socially identifiable corpse, and a vital part of the role of funeral directors. The production of a corpse that would satisfy the needs of mourners only needed to be effective for a short period of time. The wider social identity of the body for this time also marked the end of what van Gennep (1960) called the transitional period when the corpse was about to enter the community of the dead, and therefore, the status of the dead body was less ambiguous. Also, the funeral marks the period in mourning of which the deceased and the living mourning constitute a special group. Some heads of homes told me that the funeral cortege would sometimes drive past the home so that residents could witness the procession. Scheper-Hughes and Locke (1987), build on the ideas of Mary Douglas (1984), and argue that the body can be conceptualised in three forms: the individual body of lived experience, the social body as symbol and the political body subject to regulation and control. In death the dead body in its rehumanised form takes on the significance of the social body they describe. For James, who had suffered a form of social death, there was the possibility that his body could be rehumanised in its coffin, if his nephew wanted to see him.

Seeing a deceased person's body immediately after death is the next most acceptable form of visible death, and Alice received visits from all the staff on duty as part

of their farewell to her. For James, the situation was different. However, I was told by the staff that they had washed him and put on clean pyjamas, so that he would be 'ready' for the funeral directors. Even though James' body was going to be prepared professionally for its coffin, staff told me that how he looked reflected the quality of care that the home gave its residents. This is something that I had been told by staff of other homes. The state of the body of a resident reflected both in life and death, the quality of their care. I argue that the body served as a product of care as well as a site of care.

From both the commissioned study data (Sidell *et al.*, 1997), and my observations I would argue that the body is in its most taboo state when it is a 'corpse' and in the process of being removed from the home. The body had been transformed into an object, devoid of social identity. As with Alice, the body was most likely to be taken out of the nearest exit to reduce the chances of the removal being witnessed. In homes where, because of the layout of the home, the body had to be taken out through a public area, staff did their best to conceal its removal, as the head of Poplar Court said:

*We try to arrange to do it at a time when there aren't many residents around. I think it can be a little bit distressing for them.*

I discovered from talking to all types of staff about the need for this concealment that the most commonly expressed belief was that residents did not want to be confronted with the reality of death; especially when death was so close to them in time. This contrasted with the need which staff expressed for residents to be ready for death, as part of a 'good death'. It appears to be the case that the presentation of the physical reality, a spatial presence, would make the temporal closeness too real and painful. The reality of death appeared to be the sight of a dead body leaving the home and not necessarily the sight of the resident after death for, as stated above; in some homes residents said 'good-bye' to their housemates after death. The separation of the residents who lived in the home from the sight of the departing corpse of someone who died in the home appeared to contradict a frequently expressed belief by most home staff that residents who are very

old are more accepting of death. It is more likely that the body, transformed into a corpse, threatened the imminent erasure of the social identity of 'living' residents. Furthermore, the lack of humanisation of the corpse meant that it must be concealed.

Home staff frequently stated that residents accepted death because they had seen so much death during their long lives. Also they were at an age where they expected to die, and others expected them to do so. There are several problems with these explanations. First, they suggest that residents are a homogenous group who all share the same life experiences, responses and needs. Communal life however does not construct a communal identity. During the observations in the homes, and informal conversations, I found that staff constructed two main categories of residents, the collective resident group who followed general behaviour rules and those who could be called individual exceptions to the general behaviour rules. So that, for example, James was described as someone who was 'afraid of death', unlike the other residents in the home who were 'used to death'. This technique of constructing residents as ready for death is not surprising since home care staff had to manage individualised care alongside a responsibility to the whole 'living' community of the home.

Second, the staff perception of the dead body as unsightly and something to protect their charges from, placed residents in the position of passive beings in need of protection and contradicted assertions that residents were strong enough to face and accept their own imminent mortality. The way in which the majority of staff told me that they protected their residents from the sight of the body leaving the home suggested that they invested the corpse with an intrinsic quality. The body transformed into an object, which the resident had become, still had the power to produce emotions in others that needed to be controlled. One head of home explained the need to protect residents from the sight of the corpse leaving the home: *We don't want to stuff it (death) under their noses.*



The intensity of activity that was required to secrete bodies out of homes involved considerable cunning to outwit the gaze of some residents. In Autumn Lodge, James' body was removed later that evening. The next day, I discovered that a resident in a downstairs unit had become very distressed at bedtime and had to be consoled by the night care assistant. This resident told me that she had seen the hearse arrive and knew that someone had died. She said:

*The staff don't tell us when someone dies at bedtime; they don't want to upset us. But we know it's happened. They have to tell us in the end though, it's just they don't want to upset us.*

It seemed that the sight of the departing body was taboo in hospitals and homes alike. Death as a failure, despite biomedical supremacy, and death as a 'natural' event, occurring at the end of a long life and produced by home staff as the end product of a 'good death', were *both* equally unseeable. In both home and hospital settings the dead body became an object, which signified *death* and the erasure of identity at death to those who were 'dying' in a home and a sign of failure to those who were being 'saved' in hospital.

I argue from my data that staff conferred the status of something unbearable and unseeable onto the corpse. Furthermore that home staff and funeral directors colluded in this conferring of dangerous status by covering the body with sheets or placing them into thick, black plastic bags. These undignified, covered up, rather than dressed up, enclosed bodies did little to conceal them and a lot to produce the shape of death in the form of a tightly wrapped corpse. The person who had died became a concealed shape, no longer recognisable as a person, but an object, transformed into a corpse (Komaromy, 2000).

Douglas' (1984) described how the body is dangerous because the boundaries of the body are at risk of being breached by corporeal dirt. After death, the danger of spilling its contents is more intense because the body breaches the boundary between life and death. This further increases the need for containment and concealment. The body

has lost its integrity and, as described by Lawton (2000) in her study of what happened to people dying with cancer as they lost bodily control, this loss reflects the loss of self.

The explanation which staff offered me for these coverings was the need to protect and contain the potentially leaking body. It seemed that the skin of the corpse was no longer sufficiently effective to bind the body. I argue that through the process of wrapping the body after death in preparation for its removal, the coverings and its form produced the body as a taboo and unseeable object. I also argue that, having produced something unsightly it must be concealed. The consequence of this was that the most difficult journey was the exit from the place of the 'living' of which the corpse was a recent member, and this exit must also be contained and concealed. Even as the inevitable product of many homes, the dead body was still perceived to be frightening.

Leder (1990) argues that the corpse resides implicitly inside the living body, so that death is a constantly approaching future, but one at which individuals in society as living bodies cannot arrive, since, as he claimed, an individual can never be conscious of his or her own death. But the body immediately after death is more than death embodied, it is also a representation of the living person and its ambiguity is inextricably entwined with temporality. My observation of Alice's death, and conversations with staff and residents, showed that the transformation of the body that took place after death conferred a taboo status upon the corpse. Therefore, I argue that it was not so much the dead body with its varying degrees of taboo status which needed to be concealed, rather it was the departing form of concealment itself which had transformed the body into an unsightly corpse. Once this concealment had been made and the shaped anonymous corpse produced with its object-like status, the protection of the vulnerable people close to the possibility of death could be justified. The paradox was that in the morgue, as Howarth (1996) argues, the body would be prepared for the coffin in which it could be viewed as presentable and life-like. The social status would be returned and the body

would take on the identity of that person again including appearing to have died peacefully.

So far I have focused on the sight of the body of the deceased resident. I started Section 6.7.1 with graphic details about the sounds made in hospitals when bodies were removed from wards. I also described how, when Alice died, I was concerned about what residents in the lounge close by, who knew Alice well, were hearing and interpreting by these sounds. This left me to question why the same effort was not made to conceal the sounds of the departing corpse? This is what I consider next.

## **6.8 The sounds of death**

There is a paucity of literature on the sociology of sound. In a small study on people who lived in poorly sound-proofed accommodation Gurney (1998) interviewed residents about their management of noise, in particular corporeal noises and concluded that we all need to manage corporeal noise. He found that residents in shared housing who were ashamed of bodily noises covered them up with other noises.

Synott (1993) argues that vision takes primacy over hearing by tracing the senses from early Christianity through the Aristotelian politics of the senses. When Alice was being removed from Regis house, Matron did not attempt to cover the sounds, even though she closed the curtains in case anyone saw the trolley being taken to the hearse. Closing doors, crashing commodes, squeaking trolley wheels, approaching and departing hearses, all announced the departure of her corpse.

In western societies we have constructed rituals around not only what we can be permitted to see and hear but also what people can admit to having seen. I would use Goffman's (1990) 'performativity' to argue that, by denying the sight of death, it was assumed that residents could not legitimately discuss the sound and the noises which the staff made off stage since these were not presented as part of their performance. Elias (1994) traced, what he called, the *layered patterning of behaviour* in society that both

shapes and creates taboos around pleasures and prohibitions (p. 519). He argues further that this creation is in response to fear and anxieties that exist in different societies and historical periods. Furthermore, I argue that in accordance with this notion of social custom, especially in institutions, conversations behind closed doors are not signalled as public conversations in the same way that those heard in public spaces, and are less likely to be acknowledged as having been heard. In care homes what residents were not permitted to see or hear they had to pretend not to have seen or heard. These *ritualistically* ignored noises of departure of the corpse, which threatened to expose the cover up, were constructed as non-hearable sounds.

On talking to staff and residents they found that they each suspected the other was unaffected by the death. I found that the residents I talked to were very much affected by deaths in the home. It would appear that, rather than attempting to completely conceal the fact of death, professionals who disposed of dead bodies were more concerned with their *performance* of concealment. After all, as my data showed, no-one was fooled, and many residents took part in the collusion of silence surrounding the removal of dead residents from their homes. If staff did not talk openly about death, or did so in hushed tones, residents picked up strong signals that they were not permitted to discuss the event of death.

## **6.9 Summary**

In this chapter, I have traced what happened in the final days of the lives of two residents. I have argued that the staff of care homes were generally concerned that residents should achieve a 'good death'. The lack of individuality which resulted from this meant that residents' wishes were not included in this performance. The change from 'living' to 'dying' was marked by the change of routine where features of 'living', such as being got out of bed, dressed and fed, were no longer required. The continued focus on the residents' bodies through their intensity of care and the addition of pain relief, marked

a difference, even though, as in the case of Alice, pain relief might be more symbolic than instrumental.

In Regis Home the staff aimed to achieve the features of a 'good death' for Alice through the homes' practices and protocols which served to script the end-of-life care put in place by matron. What I observed was that the care was entirely physical, that Alice's pain was not controlled and was tokenistic. The routines of care that were established for James likewise involved regular physical care which centred on turning his body from side to side. As with the care of Alice, through this action, the care staff were avoiding continuous pressure which could lead to the development of pressure sores. This was part of the routine of basic nursing care, which was extensively practised in the care of sick and dying residents. On one level, the quality of care given in both homes was inscribed on the body of Alice and James, in that the presence of pressure sores would have constituted a mark of poor quality care. Similarly, cleanliness was another visible sign of 'good' care which would be read by the audience of the funeral directors, about whose judgement staff told me that they were concerned. The administration of fluids that were not swallowed would fulfil the criteria of 'good' care inasmuch as keeping James' mouth moist and avoiding thirst served some basic need. However, giving liquids that were not swallowed and which trickled out of James' mouth, but which were recorded as having been taken, suggested the task fulfilled a more symbolic purpose. I argue that the tokenistic quality of giving fluids also reflected the ambiguous nature of James' 'living'/'dying' status. The attitude of the care staff further suggested a reflection of the ambiguous status of James who was 'dying' 'out of place'; in the home rather than in a hospital. The staff had told me that he should not be in the home.

I argue further that the relationship between ritual and emotion in some ways limited the performance of the staff at the time of James' death. The ambiguous nature of a death that was out of place, compromised staff's ability to provide a convincing performance of a 'good death'. If the rhetoric of care homes was to produce 'good deaths'

as the end product of residents' lives, then James' death showed an ambiguous performance that reflected the staff's rejection of this aim. The contrast between Rachel, who had a close relationship with James, and the dispassionate care that the care staff gave to James was striking.

Therefore, despite the routines and protocols which were in place to script a 'good death', the deaths that I have described highlight the extent to which they failed to do so, as much as the extent to which they succeeded. I began this chapter with the difficulty that is associated with the concept of a 'good death'. I qualified this by claiming that, without an awareness of the needs of individual residents, achieving a 'good death' would be impossible. The ability for care home staff to get to know their residents was one of the major arguments that heads of homes gave me for being able to provide good quality care at the end of a resident's life. This care seemed to be based on the belief that every resident would want to have the same type of death, which would comply with what the staff considered to be a 'good' death.

The similarity between the type of care in the two accounts of death highlights not only the lack of individualised care, but also, the way that this form of terminal care was entirely focused on the body. In many ways, it was not dissimilar to the institutionalised care of 'living' residents. Being able to provide this care, however it was defined, was dependent upon defining the period of 'dying'. When this was not possible then there seemed to be no way that a 'good death' could be achieved.

Not just the management of the death itself but also the transformation of the body into a corpse and the removal of that corpse from the home, required a performance. It is possible to ascribe a degree of agency to the dead body, beyond that of the living person's requests made in the event of their death. The non-performing dead body seemed to have the power to produce a highly ritualised set of performances in others, mostly the home staff, supported by a cast of relatives, residents and ancillary and visiting staff. Dead bodies created responses and actions in others which went

beyond that which is minimally required in terms of disposal. Hallam *et al.* (1999) claim that:

*It is in death that the object like nature of the body becomes visible.*

*(Hallam et al., 1999, p. 4)*

Perhaps in making that 'objectedness' invisible residents were spared the sight of death? Not making any effort to conceal the sound of death suggests that it was not the fact of death that was being denied but more its visibility and everything which that was both represented and made to represent.

## **CHAPTER 7**

### **Sudden and unexpected death in care homes for older people**

#### **7.1 Introduction**

In Chapter 1, I used the example of Alice to illustrate how the materiality of ageing and dying bodies could not be easily controlled or contained. This chapter highlights how the consequences of failing to manage the unravelling of identities and bodies impacted upon the routines and practices in care homes. In particular, I consider the impact that sudden and unexpected death had on the life and routines of the homes in which I made observations. So far, I have argued that death in care homes was produced according to certain routines and protocols that attempted to script a 'good' death. I have emphasised the extent to which this was dependent upon being able to prepare for death through a categorised period of dying and the extent to which this depended on being able to predict death. I have illustrated the various signs that home staff, relatives and residents read in order to make predictions and how these were not always reliable. I have further qualified this argument by demonstrating that the reliability of these signs was less significant to staff than being prepared for death. For example, getting predictions wrong, despite the problems associated with this, I will argue, was better than missing the signs altogether. In other words, it was better for staff to diagnose a particular resident as 'dying' who subsequently recovered, than not to have recognised such a state. Therefore, despite these difficulties the process of categorisation was driven by this need which I will



show. Part of the need to predict death is explained by the premium that was placed on separating 'living' from 'dying' residents. While in many ways this was arbitrary; especially when frail and declining residents were sometimes categorised as 'living' simply through an absence of the signs of 'dying', the narrowness of the dying trajectory, defined as days and weeks rather than months and years, meant that there was a tight and unstable margin between the 'living' and 'dying' status. This, in turn, placed a greater burden on the home staff to interpret signs of the beginning of the dying trajectory.

Not only was the physical distinction between 'living' and 'dying' difficult to make for frail and ageing residents, but also the narrowness of the dying trajectory further sequestered residents within the home. The staff's failure to acknowledge the psychological pain of isolation, in turn, impacted on the withdrawal and 'fading away' of some residents. This, in turn, placed a greater burden on home staff to produce a 'good death'. As argued in Chapter 6, key characteristics of achieving a 'good death' were that it should be straightforward from the moment at which a resident was deemed to be 'dying' and medically sanctioned; that it should be 'peaceful' and that 'dying' residents should not be alone at the moment of death. Being present at the moment of death served two main purposes. First, it meant that the resident was 'accompanied', and second, it fulfilled a medical and legal requirement that the time of death should be recorded. To this extent, the legal and medical requirement for a member of staff to witness the moment of death added a professionalised dimension to death-bed scenes. This helps to explain why it was that care home staff delegated the death-bed vigil during the 'dying' phase to a lower priority than other needs in the home, usually associated with tasks of 'living', and yet, made a lot of effort to be present at the moment of death.

The focus of this chapter is on the way that the production of a 'good death' was thrown into chaos when residents died unexpectedly and suddenly, and it is the effects that result from this chaos that I explore here. By the nature of its suddenness, it was unlikely that I would be present when such deaths occurred and indeed, I did not witness

any. Therefore, the data that I draw on for this chapter come from verbal and written accounts by staff and residents. Furthermore, I did not interview any relatives following a sudden death. Sometimes other residents talked to me about an unexpected death, and I have included abstracts from some of their accounts here. In the next section I explore more of the detail of the impact of sudden death before providing examples of these effects.

First, I consider what makes sudden death so problematic and then describe accounts of sudden death that I heard from residents and care staff. I then consider how staff coped with sudden death when it occurred and the extent to which staff recovered their professional demeanour. In the final section, I offer a theoretical interpretation of what was taking place when sudden death occurred before drawing the chapter to a conclusion.

## **7.2 The problem of sudden death**

All attempts to separate out 'living' from 'dying' were thrown into chaos at the time of sudden death. In Chapter 6, I argued that the dead body was a taboo object which needed to undergo several transformations on its journey from the home to its disposal (Howarth, 1996). In talking to staff about this I noted that there were degrees of shock associated with the experience of unexpectedly finding a dead resident. I heard accounts from care staff about how shocking it was – sometimes to the point of not recovering from that shock and 'having to leave'. However, it was more than the shock of finding someone dead unexpectedly, it was also shocking that a once-living resident now occupied a 'living' space in the home in the taboo form of a dead body. The degree of shock could intensify if the space was a public one reserved for 'living' residents and open to the gaze of other residents, staff and visitors to the home. I would argue that a dead body, which once occupied a 'living' space in the home, transgressed the protocols of what 'living' spaces in the home were used for (Douglas, 1984). Furthermore, when death

forced itself into the emotional space that was usually protected by such things as professional demeanour and control, it created chaos. The result was that care staff and sometimes other residents, could no longer continue with their routines in a semi – automatic way, and instead seemed forced to react out of character. In other words, they were forced out of their routine performances associated with a 'good deaths' and into discrepant roles (Goffman, 1959).

This raised another issue. There did not seem to be any routines and protocols in place for this type of occurrence. Unlike the processes by which staff in acute emergency settings followed as scripts for sudden death, termed 'cardiac arrest' (Page and Komaromy, 2005), these events were not part of the routine of the care home. There are accounts in my data of staff transferring people to hospital for emergency treatment whom they considered as not being 'ready to die' and therefore worthy of being saved; but I did not hear any accounts of attempts made to resuscitate residents who died suddenly.

I argue that there were *degrees* of difficulty associated with sudden death. The least problematic were those deaths which could be contained and which happened in a private space, in which it could be assumed that death might occur 'naturally'; for example, in bed and in one's sleep. This did not mean that staff found this a safe place of death to cope with, because it still contained the 'horror' of a sudden death, as the accounts in the next section illustrate. The second type of problematic death was that which happened in a semi-public space but which could be concealed or easily removed. For example, residents in wheelchairs, or those who could be placed in a wheelchair without attracting attention, would qualify for this category. The most difficult form of sudden death would appear to be that which appeared suspicious in some way and so qualified as being in need of investigation. In a care home usually this would be a resident who was not considered to be ill, who had not been seen by a doctor in the previous fourteen days, and had died in a public space and with other 'living' residents

present. This meant that when the dead body could not be removed nor easily concealed, 'living' residents had to be removed from the public space, or else prevented from entering it to avoid their gaze upon death. This contrasted with the production of the unsightly corpse following anticipated death, which had to be concealed. I argue this would reveal that the staff were not able to control the event of death in an ordered and 'good' way. It also had the potential to erode institutional power by exposing the staff's failure to maintain the boundary between 'living' and 'dying' spaces. Frank (1991) and Foucault (1977) would argue that, with the dominant discourse of care in institutions centred on the rhetoric of 'rehabilitation', and the alternative of a 'good death', then, if neither were achieved, the institution had failed. Turner (1987) argues that dying is something that is regulated by norms and, as such, is socially organised. He claims that this institutionalisation of the 'dying' process avoids the contingent and disruptive events which otherwise would threaten the organisation of the institution. Furthermore, not only had the performance of predictable death production failed, but also the emotional responses by staff had not been properly scripted by the institutional norms. Paradoxically, the shock of staff when death happened outside of their control revealed the power of the system of the institutions of care homes.

The ease with which staff talked to me about sudden death suggested to me that it was acceptable for them to experience and express strong emotions associated with this event, most commonly that of shock. This emotional leakage contrasts with the concealment of the emotions of 'appropriate sadness' that it was acceptable to show in response to expected deaths. I interpreted this as supporting the view that this type of death *should not* happen. If suddenly and unexpectedly were ways in which residents might die, and clearly the reality was that this did happen, the question remains about why homes did not have protocols in place to deal with sudden death. The legitimate way of responding, which in the commissioned study heads of homes frequently told me, and which seemed to be sanctioned by heads of homes, was that care staff should be shocked by sudden and unexpected death and it was permissible for them to express these

emotions of shock. I argue that in this way, sudden death was kept at a distance, as something that was exceptional and 'other', not part of the routine of 'death and dying' in care homes for older people.

These events of sudden death also highlight the unresolved theoretical tension between what Goffman (1959) called the 'real' self and the 'performed' self. Those performances around unexpected deaths were more like the backstage activities that Goffman located as part of distancing from the social role, which he claimed some professionals exhibited, and were also part of a demonstration of essential humanity. This is how Goffman considered that people deal with discomfort especially with limited institutional support available to keep care staff in their professional roles. Staff would be in danger of acting out what he called a 'subjective reality'. To this extent, Goffman's (1990) theory of the presentation of self would explain the difference in performance around the institutionalised 'good death' and the unexpected and sudden death. In other words, the shock and lack of institutional practices and norms for coping with this type of death threw staff further along the trajectory of the 'real self' and away from the 'performing self'. However, his theory does not fully explain why it was the case that there was no script for coping with this type of death, even though it was possible to anticipate that sudden deaths would occur. In the next section I highlight some of the accounts which I heard and how staff expressed their feelings of shock to me.

### **7.3 Accounts of sudden death**

In the commissioned study (Sidell *et al.*, 1997) sudden deaths accounted for only nine percent of all deaths but seemed to cause the most concern. The following accounts from staff and residents in the homes studied in this thesis illustrate these responses.

**7.3.1 Shock induced in the staff**

*A sudden death is a shocking thing and I think this is at any age, because it is not expected; it has just happened.*

*(Marie, Head of Victoria Home)*

The head of Autumn Lodge told me how she felt about finding a resident dead:

*Shock, yes total shock, I mean I was in total shock. I know I was and the ambulance man said to me, 'Are you alright?' It wasn't the fact of seeing him dead; it was the shock of him dying when it wasn't expected because seeing someone dead doesn't really bother me. It's just the situation that I'm in that shocked me more than him dying.*

This account conveys some of the emotional impact that sudden death had on care staff. The emotion of shock seemed to dominate and stay with the staff long after the event. Sometimes this state of shock was compounded by the body itself becoming an object of which to be afraid. In the field notes that follow Josie explained how she coped with this shock that followed finding someone dead.

**Fieldnote: Night duty**

I waited until the night staff on duty had finished their main routine tasks and then sat down with each one on each floor to discuss the subject of 'death and dying'. Josie told me that she didn't really mind when someone died at night, but finding someone dead unexpectedly was a very different experience.

We talked about the ways in which she coped with 'death and dying' and she told me:

*I am not afraid of dead bodies – of seeing the dead body of a resident – if I have been with them when they die. It's funny really – well not funny but*

*strange, I mean – erm, well, I don't like to go and see someone after death – it's like they're not that person anymore and a bit scary, really.*

I wanted to explore this further and I tried to get her to explain and she told me she had no idea what it was about. She then changed the subject to her concerns about not having enough staff to sit with Doris who was thought to be 'dying'

Josie's account suggests that the body could become strange and an object and no longer identifiable as the resident she knew. Whereas it seemed that, as long as Josie was with that resident at the moment of death, she was able to recognise him or her as a deceased resident, rather than a body made strange and fearsome by death. Not only did Josie construct the discovered dead body as being 'other' than the deceased resident, her account also highlighted how unexpected death at night was something that took on a more frightening dimension than one which occurred during the daytime.

### **7.3.2 Residents' shock**

A few residents told me that they wanted to be 'taken' because they had 'had enough'. In Chapter 6, I provided accounts from Mabel and Alice in Regis Home, who told me that they prayed for the 'Lord' to take them 'quickly'. These accounts echoed that given by Betty in St. Mary's House who talked about the inappropriateness of a lingering death. However, it seemed to be a less desirable way to die when it involved a fellow resident dying suddenly. For example, following the death of a male resident in Peacehaven home, Masie, a fellow resident, told me:

*I still can't believe it. He was a great big strapping man and he went to bed and that was it. We were (...) well, we never saw him again. It still upsets me like. I mean, you never know.*

This account by Masie suggested that there was an apparent contradiction at play. If the deceased resident was such a powerful man, how was it possible that he was unable to withstand death and could be so easily struck down? This created fear and uncertainty in Masie. It seemed that if death could strike down the powerful, without warning, then perhaps anyone could die at any time. Masie has given death the power of agency. In her account residents did not die because of some biological event, which would coincide with the biomedical explanation of disease, rather, death was something external to everyday experience and quite arbitrary.

In the extract from my fieldnotes from Poplar Court that follows, I describe how Bob's best friend Phil died suddenly and how he described its impact upon him.

### **Fieldnotes: Losing a friend**

#### *Monday afternoon*

One of the care assistants, Melanie suggested that I might want to talk to Bob because he was 'withdrawn' and she suspected 'waiting to die'. I made a brief visit to him before I went home and asked him if I could talk to him the next day. I explained that I was looking at the quality of life in the home and I would explain more about it tomorrow. He didn't seem to want to know any detail and agreed to see me at 11 am the next day.

#### *Tuesday morning*

I knocked at Bob's bedroom door, which was slightly ajar. Bob told me to *come in!* and I entered his room. He was seated in a wheelchair next to his bed and was doing something with the papers on his dressing table, adjacent to the bed and situated under the small net-curtained window. The room was of average size and contained a bed which was pushed against one wall, a small armchair, a commode and a dressing table covered with photos, papers and Bob's medication, kept in a small plastic ice-cream container.



*Hello Bob, it is good of you to talk to me, I said.*

He nodded at me but did not smile. He looked very sad. I asked: *How long have you lived here, Bob?*

He told me that he had lived in the home for just over four years. I asked him if he had any friends in the home and he replied: *No, I keep myself to myself now – it's better that way.*

I asked him what he meant by 'better'? *I don't want to make any attachments no more.*

He went on to add: *I had a very close friend here and we was really good mates, but he died.*

I asked him how his friend's death had affected him and he started to cry. (I knew that the death had occurred two months previously and had been a sudden death):

*It's completely shaken me, there was no warning, he was gone, just like that (he clicked his fingers) (...) and strangely enough, shortly after his death, I became ill myself! Aye, that were just after Phil's death. We were very close. I didn't go to the funeral 'cos I couldn't manage in the wheelchair, you know? Mind you, they had the funeral tea in the home here, you know, and I was invited. I was pleased about that 'cos I could sort of erm, mark his death some how.*

It seemed clear that Bob was grieving for his lost friend and was afraid to risk another friendship in case he had to endure the pain of loss again. In this way it was possible that his withdrawal was a form of self-protection. Bob told his story very easily without any prompting. He seemed to be preoccupied with his loss, and yet, the care assistant told me that he did not like to talk about his 'lost friend'. Bob also made a connection between

the shock of his friend's death and becoming ill, as if the shock made him ill. As he stated, 'It's completely shaken me.'

Bob was pleased that he had been invited to the tea in the home and I would argue that this acknowledgement of his friendship attributed a higher status to his relationship with the deceased resident, Phil, and his place in the bereavement process. It also suggests that making arrangements to get Bob to the funeral would have been too difficult and the funeral tea offered a more convenient alternative. Because Bob was in a wheelchair he would have required special transport *to* and some assistance *at* the funeral, and such an effort might have only been made for a significant person in the life of the deceased. Those residents that I talked to about acknowledging the death of someone close in the home told me that they would attend a home event, but not an outside funeral service. The role of residents at the funeral suggests a more ambiguous role. I noted in Chapter 6 how, when Alice was dying, her 'outside' friends' right to visit the death bed took precedence over the residents in the home, including her close friend Martha, who was relegated to a vigil in the dayroom near to the corridor to Alice's room. Bob's story supported my observation that relationships formed inside the home did not seem to have the same currency as those which had their roots outside of the home.

### **7.3.3 Death out of place**

In the UK, unexpected deaths are treated as suspicious deaths in that there is a legal requirement for any death to be reported to the coroner (Department of Health, 2003). Therefore, if a resident had not seen a doctor for fourteen days prior to his or her death, an autopsy might be performed to ascertain or confirm the cause of death. This is the case for all sudden deaths. In the commissioned study (Sidell *et al.*, 1997) I heard accounts of sudden deaths that were suspicious, taking place in public areas and residents being kept away from this apparently shocking sight. One of the worst consequences for residential care homes was that a suspicious death in a communal area

meant that the body could not be removed until it was legally sanctioned for the home to do so. The following fieldnotes from St. Mary's House illustrate the distress that this caused home staff.

### **Fieldnotes: St. Mary's House night staff**

One of the permanent members of night staff, Tracey, told me that during her time spent working in the home she had found three people dead at night. She went on to tell me:

*They were all very shocking for me. The police were called and they stay with the body until the undertaker comes. We don't lay them out – we're not allowed to touch them.*

Tracey added that she found death very difficult because she did not *really understand what death meant.*

She talked to me about her own mother's death and how deeply this affected her. She then went on to say: *They are all someone's mothers – and that is how I see them now.*

Anne was an experienced senior care assistant at St. Mary's House. She told me about her experience of death at night and included how sudden deaths were managed:

*If the death is totally unpredicted – as a sudden death is – and if the GP has not seen them for the previous three weeks, then the body has to be left in exactly what position it was found in. I mean this could be on the commode, half hanging out of bed, on the chair – or even collapsed in the corridor. Then the police have to be called. They stay until the GP comes and examines the resident and issues – or doesn't issue – a death certificate, depending on whether they are a locum – and the police 'guard' the body until it goes to the mortuary. They even escort the mortuary ambulance – usually to the hospital.*

Anne went on to tell me about how this was what she called: *Really horrible* and how *it makes you feel as if you're under suspicion of having killed them – I don't understand why they do this.*

She also told me that she disliked having the police in the home for hours and emphasised how it made her feel '*horrible*'. She explained that the undertakers were sometimes busy and weren't usually in a hurry to collect a dead body, because, as she explained: *Nothing is going to happen to them.*

Anne recounted a story about a resident who had been admitted to the home with her husband. She explained to me that it was:

*The woman who was quite ill and it was because of **her** needs that they had decided to come into the home. However, on the first night, her husband suffered a massive coronary and died.*

She explained this as '*shocking and disturbing for everybody*'. Anne said: *It was made particularly difficult being a sudden death because these people were only admitted that day; if not more suspicious.*

She explained, *I don't know why it would be **more** suspicious if someone just came into a home.*

Care home staff told me that they tried to make the dead body 'presentable'. The following quote from the head of Church House, typifies many of the accounts which I heard:

*We just make them tidy, make them as presentable as possible, especially if the family come in. We want him or her to look as nice as possible, so the family can go and see them*

Following a sudden and unexpected death, this would be very difficult and the dead resident, who independently claimed this status of sudden and unexpected death, could not be made presentable as easily as the body of a resident whose death had been anticipated.

I would argue that these accounts illustrate the way that care home staff needed to recover from the unpredictable event of sudden death. However, the 'suspicious' nature of the death and the legal surveillance of the body, made this type of death particularly difficult to manage. In Chapter 6, I argued that the dead body became a taboo object. In homes where death was dangerously close to ageing and frail residents, the boundary between life and death needed to be maintained. One of the measures for maintaining this boundary was to separate those residents who were 'living' from those who were 'dying'. The body as a shocking object and which, in those circumstances, had to remain in the same space, became an undeniable reality of the arbitrariness of death. The dead body in a public space not only transgressed the 'living'/'dying' boundary, but bypassed it altogether. As such, it seemed that the dead body could potentially pollute the 'living' spaces of the home. The care home staff, who could normally be relied upon to manage the events of 'living' and 'dying' through a professional performance, seemed to be powerless to keep separate or fully conceal, the event of unexpected death. In this way, their own professional competence was threatened. There was no evidence in my data to suggest that residents shared the same need to maintain such boundaries. However, not many residents raised the topic with me and I did not actively seek their views.

The state of shock which most members of staff talked to me about affected their ability to maintain a professional identity. The reality that the death had to be reported to a coroner and that the staff were not able to anticipate that death was imminent also produced feelings of guilt and this is what I discuss next.

### 7.3.4 Unease/feelings of guilt

A staff nurse in Victoria Nursing Home told me:

*The worst thing is finding them in the morning in bed. You know that they have been checked at six o'clock and you go in at eight o'clock and they are gone. It makes you wonder whether they were in pain; whether they needed anyone.*

The features of a 'good death', which I described in Chapter 6, included not being alone at the moment of death. This contradicted the wish that some residents expressed to me to be able to 'die in my sleep'; although surviving residents and relatives did not always agree that this was a 'good death'. However, it was clear that the margin between dying suddenly and not having a 'lingering' death was narrowly defined, because as some of the accounts in Chapter 6 highlighted it was possible for residents to outstay their welcome. I would argue that those members of staff who talked to me about how a sudden death could be 'better than a lingering death' drew on repertoires of compensation (Wetherell, 2001). Discourse analysis theory shows that in explaining those events that seem to be difficult to cope with, people seek out ways of mitigating this difficulty and use commonly shared 'compensatory discourses'. I heard many such repertoires as part of the compensation for the death of individual residents, regardless of the type of death. However, it was more common to hear these compensatory repertoires following difficult deaths. Jackie, a care assistant in Seaview home told me that:

*Olive's death was a blessing as the end of suffering, because she lost all her dignity. She was blind, deaf and had to have everything done for her. In the end she was just skin and bones.*

Other difficult deaths included those where a resident had died alone, and for which one compensation was that he, or she, did not know anything about 'it'. This was offered as compensation for the fact of residents being alone at the moment of death. Tracey, in Peacehaven Home, whose account of sudden death is included above in Section 7.3.3, went on to tell me:

*I think if you were to ask the residents they would tell you that they would prefer to just die in their sleep.*

One of the care assistants in Autumn Lodge told me:

*It's best to know nothing about it – to die in your sleep. That's what I think people want, really.*

The head of Seaview, Mrs. Stoney told me:

*Residents are particularly concerned to hear that people die in their sleep. I think it is important for people to work out how their own death might be. I think that a sudden death is better for them than a lingering death, because they are not fighting to stay alive. They have slipped away unnoticed. There is something to say for that, although I know that if I found someone, I am not sure I could cope.*

One of the ways in which staff might cope with sudden death was in the successful concealment of the dead body from other residents in the home.

## **7.4 Performance – 'bringing off' being professional at a time of chaos**

Rosie, the head of Victoria Care Home told me how she managed to conceal the death of a resident who was about to go on the transport home from day care:

*They wheeled the chair to the day care door, ready for the transport, and I sort of looked at this lady and I knew she was dead. (Pause). I just quietly wheeled her down to the units to the short-stay beds, which I knew was vacant, just to check really that I was right before 'phoning the daughter. (Pause). So I did 'phone and I said 'I have got a problem', so I wasn't telling any lies, 'and I would like you to come to the home.' She said, 'What is it?' and I said, 'well, I prefer to tell you here'. And she came and that was it.*

Vialles' (1994) study helped me to recognise how the symbolism of putting the corpses of animals into positions that they would not occupy when alive was also relevant to these accounts of coping with sudden death. In her anthropological study of abattoirs in France, Vialles (1994) argues that the division between living and dead animals is tightly controlled both through the layout of the abattoir and the practices within it. While she noted that this separation between living and killing were important on very practical grounds, there was something else taking place that suggested what she calls a 'deanimalisation', symbolised by the way that the animals' feet were lifted from the ground. Vialles goes on to explain that, after death, an animal was kept elevated above the ground and no longer able to adopt the position of living animals with their feet on the ground. In this way, animals were 'killed' before the moment of slaughter by being arranged in space in particular ways. I would argue conversely that residents who died in the home could be kept 'alive' through the staff strategy of positioning them in space as 'living' bodies.

From my data, I argue that divisions between life and death were made by practices in particular spaces, by treating the dead body as a 'living' one, Rosie was able to 'bring off' the concealment of death from other residents and trick any observers into thinking that the dead resident was still alive. She did this by making the resident appear to be doing what 'living' residents would do. Even though to Rosie's expertly trained eye, it was clear that the resident was dead, Rosie made the body perform a 'living' task, that of being moved around the home in a wheelchair, rather than keeping the body still and flat in the way that a dead body should be treated. These practices that related to 'living' bodies would be taboo for dead ones. Dead bodies were usually kept flat and were not moved around the home unless in the process of being removed from the home by the undertakers, which would only happen after the body had been transformed into a corpse.



While it was the case that in sudden death the body could be concealed by being made to behave as if it was 'living', so its occupation of a living space, without the trick of concealment, could create great distress. For example, one head of home whom I interviewed, told me about the distress that her staff expressed when a resident who had died was left sitting in the chair at her family's request until they could get to the home to see her. Even though it took them many hours to get to the home, the head of home agreed to their request, but met enormous opposition and disapproval from her staff, as she explained to me:

*I rang the family and told them and they wanted me to leave her in the chair, where she had died. I said I was happy to do that even though it may take them as long as five hours to get here from London. The thing is it was the staff who found it difficult - they didn't think it was right to leave her there in the chair. In fact, I was surprised by how much anger it caused in the staff. I was determined that the family were going to get their wish and I told them this was the last word on it, but they didn't like it.'*

Vialles (1994) calls the moment of slaughter 'the end of the road'. Likewise, my data show the transition from 'living' to 'dying' resident was one-way. Even though some residents did not go on to die at the predicted time, they did not usually re-enter the space of 'living' in the home; occupying instead a liminal space. In Chapter 4, I discussed the way that Grace, in Seaview House, having once transgressed the 'dying' boundary, was neither 'living' nor 'dying' and, rather, suspended in a liminal space between both states.

I argue further that, at the time of sudden death, and through the agency of their dead body, residents became suddenly more powerful in that the agency of the dead body was carried in the staff activities after death. For example, in anticipating death a resident could make post-mortem requests about what might happen to his or her remains. Even if it was not the case that a request had been made, the post-death rituals

and routines were enacted in response to the appearance of the dead body. In this sense the dead body carried agency, through its existence and in having the power to cause certain actions in response to it. Quite crudely, it could not be ignored, just as Lawton (2000) argued that people without the possibility of recovery ceased to be the agents of their own actions, so it was with resident's dead body. At the time of sudden death this 'object-like' body impacted upon the bodies of these carers to the extent that it dictated their actions. In the section that follows I offer more theoretical interpretations on what was taking place at the time of sudden death and why this might be so problematic for staff who had not carried the heavy burden of terminal care.

## **7.5 Sudden deaths as 'bad deaths'**

My analysis of the data suggests that for the staff of care homes, sudden death was the worst kind of death for them to encounter because of its shocking nature. I have argued throughout this thesis that the care home staff had to find ways of coping with the difficult job of managing the dualistic nature and territories of 'living' and 'dying' residents. Despite the recognition by some staff and residents that a sudden death could provide a 'good death', the problems that were associated with this type of death in care homes seemed focused on the dead body itself. The appearance of an unplanned-for dead body threatened that 'life/death' boundary and the performance that enabled staff to carry off 'good death' scenarios. In this section I draw on the theories of Douglas (1984), Goffman (1959) and Hochschild (1983) to explore ways of making sense of this apparent contradiction.

Douglas (1984) argues that things are not of themselves intrinsically 'dirty' or 'polluted', rather it depends on where objects are placed which dictates the extent to which they become 'dirt' that is matter out of place. Douglas (1984) further argues that 'pattern-making' tendencies in us all mean that we 'construct stable worlds' (or schema) which makes us locate objects within a 'system of labels', so that these objects which do

not fit the schema create discomfort or feelings of anxiety. These individual constructs are mediated by the cultural values and categories and form a rigid pattern. Therefore, providing an order to cope with 'dirt', in this case the dead body, was one way of sustaining the system; or what she calls the 'order of things'. However, as my data show, when a residents' dead body, was in a space reserved for 'living' residents this contravention of a rigid pattern threatened to contaminate the otherwise 'clean' space of 'living'. The outcome was that the suddenly-dead body revealed the arbitrariness of the 'living' and 'dying' categories and this resonated with the reality of the imminence of death. I argue that at the time of sudden death it is as if all of the systems that were drawn on to make something difficult more manageable and provide a particular meaning were thrown into chaos and thus all were in danger of becoming meaningless.

Just as the boundary in the abattoir that Vialles (1994) describes enabled those working there to cope with the reality of what took place, so too, I argue, in care homes, staff had to cope with the reality that most residents would die there. Thus, while the abattoir workers transformed the dead animals they produced into edible food, so too, the end product for the home staff was a body that could be removed, usually without being seen. Howarth (1996) also argues that the contaminating effect of the corpse explains the need for its immediate removal from domestic settings. I would argue that in institutions the symbolic dangers of contamination are even greater. My data have shown that following a sudden death in a care home the dead body had the potential to be highly 'contagious' and any restrictions on its removal created great distress to the staff to whom I talked.

Douglas (1984) further argues that the dead body, as a container of death, is not just a potentially polluting object, but the human body is also a symbol of boundaries in society. In the care homes in this thesis, after-death care involved attempts to make the body patent, although much of the packing of bodily orifices was performed by funeral directors and no longer carried out as a routine part of last-offices. Constructing the body

as a potentially leaking and polluting entity was less in evidence in anticipated death. What was striking, by contrast, was the way that, at the time of sudden death, the body became exceptionally dangerous and taboo, mainly because it was occupying the 'wrong' space. In the form of the body having transgressed the life/death boundary is what Douglas would refer to as matter out of place. This was the case, regardless of whether or not the space was private or public, although, as I have argued, its relative visibility to others influenced the degree to which the space became extremely problematic, not least because the suddenness and unforeseen nature of the death had not given staff time to sanction the space as 'non-living'. I also argue that this made the event of death and its material form of the dead body, uncontrollable and therefore, such a form of matter carried symbolic terror. This was the body at its most dangerous. Death that was close to the boundary of life, as was the case when it lurked within these frail and failing bodies, not only had the potential to pollute those considered as 'living' in the home, but had demonstrably done so already and could do so again.

Throughout this thesis, I have discussed how the care home staff needed to be able to make a convincing performance at the time of death, through routines and rituals, largely directed by more senior members of staff who were experienced in death. To be effective as part of a 'good death' this performance needed to be produced as the 'natural' outcome of a long life, as part of the way that a 'good death' was scripted in care homes. Anticipated death could be managed in this way and routines existed that eased the residents' passage through this final phase of their life. The routines also served to distance staff from the reality of death and loss, and helped them to manage the anxiety and existential terror that surrounds death. In this way, death that was anticipated, could be tamed and controlled by the practices that were put in place to enable staff to routinely respond to it. In Goffman's (1961) terms, death as something that existed within an institution was produced in a way that met the social expectations of the audience, in this case it was those members of staff not immediately involved, relatives and friends and surviving residents.

By contrast, at the time of sudden death, staff talked about their feelings of shock and being unprepared. It seemed to be a difficult task for them to be able to produce sudden death as a 'normal' event. The accounts that I have used illustrated ways in which staff were able to recover the situation, but it seemed that, apart from the legal requirements to notify the coroner of potentially suspicious deaths, there was nothing in place to script their behaviour and so make this distress more manageable. In this way, sudden death shook staff out of the rehearsed ways of responding. Despite this, it seemed that there was still a need to be able to perform a socially condoned response to sudden death. Goffman (1959) argues that a good performance demands that people do not show the emotional 'ups and downs' of their moods and performances. Certainly this seemed to be a time when this was severely tested, as the requirement to be composed at this time of potential chaos and distress was much greater. Hochschild's (1983) resistance to the commercialisation of emotion, as part of a professional response to exceptional demands on the professional role, offered a more convincing explanation.

Goffman (1959) further argues that everything involves performance in as far as the whole of life involves social ritual. The findings of my field work support this to the extent that staff had to stay in their role as a member of the home care staff and, as such, behave as the person who was expected to cope with the event of sudden death as part of their professional role. However, as noted earlier, I was surprised to find that, unlike acute hospital settings, where there were strategies in place to cope with unexpected events, there was nothing available in care homes. This was more surprising to me when I noted that all homes had some sort of fire drill on a regular basis. Those staff to whom I talked about their role in the event of a fire were clear that their role included getting residents out of the home, if this was possible, and making some attempt to limit the spread of fire. Certainly, the event of a fire was less of an occurrence than sudden death and none of the staff to whom I talked had been involved in a fire. However, this did not explain why there was nothing in place that would help staff to manage these relatively frequent (compared with fire), and yet, devastating occurrences

of sudden death. I would argue that this limited the extent to which both the theories associated with performance and the polluting effects of the dead body explained why there was nothing in place to cope with sudden death. In the next section I offer an alternative explanation based on my data.

## **7.6 Conclusion**

In this chapter I have argued that taboos can vary in intensity, and that the lack of separation of 'living' and 'dying' which can result in 'death' in the midst of 'life' nonetheless operates in different ways depending on context. The worst kind of sudden and unexpected death was that which took place in a public space occupied by home residents and which was considered to be 'suspicious'. The least awful death was that which took place in the private space of the home; although the staff who described their reactions to me, expressed feelings of shock which seemed to persist over long periods of time. Regardless of any spontaneous coping mechanisms that staff deployed, the chaotic event of sudden and unexpected death temporarily broke down the boundary between 'life and death' and made this a highly emotionally charged event.

This form of denial of death was accompanied by an unusual display in these care home settings. The acceptable process of death in the institutional care home was that which was controlled by care staff in the ways that I described in Chapters 5 and 6. I suggest that death that was out of time and out of place and which had contravened the prescribed care-home death, would not be taken into account. Just as sudden and unexpected death broke the boundaries of acceptability and then transgressed the tightly controlled territories of life and death, so too the home staff spoiled their professional performance of control. Without an acceptable place for sudden and unexpected death, there was no professional code for care staff to follow. 'Dying' outside of the approved trajectory, and thus, 'dying' out of control in a total institution, where the staff controlled every aspect of a resident's life meant that they died without 'permission' and this

contravened the rules of the institution (Goffman, 1961). Unlike the staff in acute settings who manage their emotions according to the performance in response to sudden death, (Meerabeau and Page, 1997) , the home staff did not attempt to control this event by having procedures in place. I argue that this absence, served the purpose of continuing to 'outlaw' the event. Furthermore, the lack of accommodation sustained the unacceptability of an unpredictable event in institutions where the premium was on sustaining the maintenance of the blurred and fragile boundaries between 'living' and 'dying' and life and death. To accommodate sudden death through routines and procedures would threaten the existing productions of the 'living' and 'dying' categories and might lead to total chaos.

## CHAPTER 8

### Working with ghosts

#### 8.1 Introduction

In this final chapter I return to the questions I posed in Chapter 3 and briefly explore the extent to which I have answered them. I return to the choice of thesis in terms of what I chose to include and reflect on the process of the research experience and my role as a researcher in this type of study. Because I want to acknowledge the influence of the residents who died and those people from my professional and personal life who influenced my interest in the subject of death and dying, and who subsequently died, I have entitled this chapter 'working with ghosts'. Finally, I suggest what the thesis might contribute to the practice of caring for older people in care homes.

#### 8.2 Rhetoric and practice

I began this thesis with an explanation of why I wanted to explore the gap between the rhetoric from interviews with heads of homes in the commissioned study (Sidell *et al.*, 1997) and the practice of managing 'death and dying'. In essence I wanted to explore what happened at the time of death and dying and how this was different from what heads of homes told me at interview. Underpinning their rhetoric about death and dying was the aim of homes to enable residents to be able to achieve a 'good death' that was underpinned by an assumption that there could be such a thing as a 'good death'. In order to investigate this I needed to:



- Explore how 'dying' was produced in the care homes as different from 'living'.
- Explore what happened when residents were dying and around the time of death through direct observations.

I spent over one year in the field collecting data and this provided rich accounts of death and dying. I would argue that the data which I have presented in this thesis, have done more than highlight the gap between rhetoric and practice, they have also shown the human face of 'dying'. However, the main outcome of this research is that I discovered a new form of marginalising older, 'dying' people, not through their sequestration into institutional care homes, although that clearly happened, but much more through the production of 'rehabilitation' as 'living'.

Throughout this thesis I have drawn upon three disciplinary areas of literature to help me to interpret my data. First, Goffman's (1961) definition of the concept of total institutions helped me to interpret the day-to-day lives of the residents in those care homes which I studied. Here, Goffman draws on his work in his three-year study of psychiatric inpatients whose lives were regulated under one roof and following one rational plan. The scheduling of activities in groups is a form of regulation which he argues controls the daily activities of the lives of inmates and defines their identity. In his definition of total institutions he included hospitals, prisons and home for older people among other institutions. Most significantly here, his work contributed to the backlash against the dangers of institutional life. I have drawn on theories of symbolic interactionism, and, more specifically, Goffman's (1959) theory of performance, performativity and impression management, to consider how death and dying in care homes was produced. The second main strand of literature has been anthropological, mainly drawing on the ideas of Douglas (1984), which helped me to explore the 'symbolic' dimension of this interactionism. Finally, in order to understand what was happening to the ageing and dying bodies of residents, I drew upon the literature of the sociology of

the body (Turner, 1992, 1996; Tulle-Winton, 2000; Foucault, 1979). I consider each of these in turn.

During the content analysis of my data, I developed the three metacategories, of 'bodies' in 'space' and 'time'. I drew heavily on ideas of performance to consider the ways in which 'death and dying' were produced, in particular how 'dying' was produced as being different from 'living'. This literature helped me to see that those interactions that constructed 'living', 'dying' and 'death' were *symbolised* as routines. The dramaturgical metaphor (Goffman, 1959) also helped to explain the way that heads of homes managed the 'front stage', and that this was where the social identity of residents as either 'living', 'dying' or 'dead' was established, in other words where 'living', 'dying' or 'death' was produced. Goffman has been criticised within sociology for being too concerned with the minute detail of interactions (Meltzer *et al.*, 1975), so much so that he has been accused of crossing the disciplinary boundary of psychology by ignoring the structural aspects of society. Indeed Giddens (1979) would argue that human agency and social structures are interdependent. While, I would support the iterative relationship between structure and agency, I would argue that, in many ways, his explanation of how institutional power is located within the routines and practices of homes as institutions suited my own study. The fact that his theories do not explain the wider social structures and processes of power was not a problem for such a small-scale ethnographic study.

Certainly, the way that care home institutions controlled bodies in space and over time can be identified as a form of power. However, my data showed that this power was more fluid, rather than fixed and one-way, as Goffman's (1961) view of total institutions suggests. I argue that, not only was power more diffuse, but also that my data showed both staff and residents resisted forms of power and Foucault's (1977) theory of disciplinary power which argues for a more subtle interpretation was helpful here. It was also the case that the practices and routines within care homes themselves were resistant to certain types of death; and I have provided examples of 'bad deaths', in the form of

sudden and unexpected deaths, and deaths 'out of place' to illustrate these extremes of resistance. Furthermore, staff performances around these deaths that Goffman (1959) might call 'discrepant', did not explain the resistance to and failure of a convincing professional performance at the time of sudden death in ways that would successfully conceal the emotional turmoil that resulted from them. This emotional leakage that occurred needed a different theoretical interpretation. Furthermore, interactionism did not fully explain the differences between and within care homes, so that, rather than the commonality between institutions that is suggested by Goffman's (1961) concept of total institutions, I found that institutional roles and rules were interpreted differently. More fundamentally than this, interactionism does not explain the extent to which the roles that were played out were useful to any staff, residents and relatives. Therefore, I would argue that, one of the key problems with an interactionist approach to interpreting my data was that, according to Goffman's notion of the effects of institutions on its inmates, power as a negative and repressive force was not entirely helpful. Indeed, I did not find this to be the case and rather, would argue that the use of power in care homes for older people was much more productive, nuanced and diffuse.

By contrast, Foucault (1977) argued that power, while embedded in discursive practices and régimes, was polymorphous and diverse. By this he meant that it is no longer possible to trace power along a hierarchical path to its source, rather, power exists within such things as the discursive regimes, which flow from professional discourses. According to Foucault, these new forms of power, which he calls 'technologies of power', and which have been the focus of much of the literature on the sociology of the body, produce, rather than control and repress, the body. The body as something that has been produced, rather than suppressed or controlled, allows for an appreciation of the resistance as my data showed. For example, in my data, the ageing body failed to perform all of the tasks of 'living', 'dying' and 'death'. I have interpreted the way that these bodily resistances to being categorised in such ways produced a gap between the category and the 'realities' of what was taking place, and have suggested ways in which

this gap served as part of the evidence for symbolic elements of performance. However, while a Goffmanesque interpretation would support the argument that the power in practices and routines is symbolic rather than instrumental, there remains a misfit. What I mean by this is that the *need* for symbolism, which is part of the nature of institutional practices, also needs to be explained. It is not enough to claim that institutional practices and routines were symbolic, without explaining the function of particular symbolic acts. In my data, I have suggested that they served several diverse purposes. Most significantly, I argue that one fundamental reason was to help maintain the boundary between 'life' and 'death', and that, as part of the maintenance, 'living' and 'dying' bodies needed to be monitored, categorised and separated. For example symbolic actions such as giving pain-relieving drugs that did not relieve pain; feeding and pouring liquids into the mouths of residents, who did not swallow them were also part of the production of 'living' and 'dying' that served to sustain the boundary between 'life' and 'death'.

The anthropological literature that helped me to consider the reasons for the need to maintain boundaries was primarily drawn from Douglas (1984) and van Gennep (1960). These anthropological explanations of the symbolic nature of boundaries and what these might represent helped me to develop an interpretation of my data, in particular, the symbolic significance of bodies in the maintenance of boundaries especially around the highly taboo 'life/death' boundary. However, I argue that one key disadvantage is that, while the theories explained the need for boundaries, they did not explore the experiences associated with approaching and crossing them. I will argue later that failure to recognise this experience left the 'dying' person in isolation.

I have argued that the variation in resistance to practices, roles and routines was, in part, emotional. Despite the criticism that Goffman is located as being nearer to theories that explain the behaviour of the individual at the psychological or psychosocial level of explanation, Goffman offers an explanation of the individual that is entirely social. According to Goffman, the individual self is social in that it is made out of the same

materials as the performing self. Accordingly, the self is always in a state of performance. I found it difficult to answer whether or not the emotional demeanour of care staff and residents were part of the performance or were emotional displays of more individual 'authentic' feelings, which they were unable to contain and separate from their ascribed role. In this sense, their emotional displays could be interpreted as forms of resistance to how they were expected to be either as an older resident or as a professional carer. But there was something much more puzzling about the consistent nature of responses to sudden death, in which emotional displays of shock and horror were condoned and even expected. These suggested a lack of individual diversity and challenged the extent to which people displayed individualised emotions outside of their roles. In Chapter 7, I argued that this was a form of institutional resistance.

However, there is another level of enquiry that is worth exploring. It is possible, that in the form of the corpse that appeared unexpectedly in a space where 'living' was produced the dead body held a greater taboo status and therefore needed an appropriate (universal) emotional response. Likewise social expectations of feelings of loss and sadness associated with death in many aspects of western societies become régimes of truth (Foucault, 1979) that shaped emotional responses to death. On one level, I have speculated about a Goffmanesque interpretation in which the behaviour of everyone involved in the production of death was part of a performance of the presentation of 'self'. On another level, Hochschild (1983) argues, that the commercialisation of feeling that is part of any professional role, is abandoned when there are demands that position the emotional demeanour as a luxury and one which is sacrificed at times of what she calls 'speed up', when the pressure of work increases. Her explanation offered some insight into the emotions that care staff expressed at the time of sudden death, as if this type of performance might be a bridge too far. I would also argue that this form of resistance to producing a 'good death' out of the material of a 'bad' one was more likely to fit the institutional drive to produce either rehabilitative 'living' or a 'good death', and not 'bad' deaths. With the entire focus of the practice of care homes on rehabilitative 'living',

followed by a narrowly defined period of 'dying', this would explain why there was no script for any other form of death and how those deaths which were more achievable as 'good' were only possible if the period of dying was not too long or complicated. Therefore, I argue that all of these aspects of performance, power, resistance and emotional labour were played out to varying degrees of ease and discomfort. Just as the ageing and dying body unravelled its way to death, so too forces and constraints which both shaped and responded to its management were entangled and messy. Therefore the different theoretical interpretations offered different and complementary forms of explanation that deepen an understanding of what was taking place, rather than presenting competing perspectives and thus being oppositional.

## **8.3 Reflecting on the content of the thesis**

### **8.3.1 Choosing what to exclude**

In writing this thesis I had to make choices about which data to include and which to exclude. It is worth reflecting on what I excluded. Much of the data that framed the findings in this thesis have been excluded from this analysis. I would argue that these aspects formed an essential part of the context in which this thesis is situated and which I included in Chapter 3, where I provided detailed descriptions of the location, type and size of homes and profile of residents.

The interviews that I conducted with GPs and community nurses raised many issues about the way that support was given to homes and the process of negotiation for this support that took place between the home staff and supporters. One of the main issues that affected the way that 'dying' residents were cared for involved transfer decisions. During the two years that I spent on data collection for this thesis and the commissioned study (Sidell *et al.*, 1997), it began to emerge that there was a movement of residents between hospital and different homes. The changes in hospital profiles and

the changes in the status of care homes, meant that I was seeing some of the dilemmas that were increasing, not only about the state of 'living' or 'dying' of residents but also about the appropriateness of the place in which residents should die. I have written about this elsewhere (Sidell and Komaromy, 2003). In this thesis, James' death, which I described in Chapter 6, included a perceived need to transfer him out of the home, which was a prominent feature of the way that 'dying' was produced and which contributed to his death as one that was 'out of place'. This returns to the point I made earlier in this section about the qualification, training and resources available to care homes.

These issues were relevant to my thesis and impacted upon and framed the space within which care was delivered and on which I focused my observations and analysis. Furthermore, these structural issues, which formed part of the wider context and which framed the way that 'death and dying' was constructed in care homes, provided the evidence for the recommendations that were made to the Department of Health in the commissioned study (Sidell *et al.*, 1997) (see Appendix 1). However, I would make an important distinction here, in that the report that followed the commissioned study did not offer any theoretical interpretations of the data, beyond their location within other studies. The report was almost entirely focused on the physical factors and constraints that affected the quality of care that 'dying' residents received, as part of the exploration of the need for palliative care in these settings. The observational data provided descriptions of events that occurred in the home as they impacted upon terminal care delivery.

## **8.4 Reflection on the process**

In this thesis I did not want to take things at face value, rather I wanted to explore in depth, the practice of 'death and dying'. I discussed the need for a reflexive approach to this type of ethnographic study in Chapter 3. Here I return to some aspects of this reflection.

I would argue that, one of the strengths of writing a thesis part-time was the benefit that accrued from being able to reflect over a longer period of time. For example, I had noted that the staff of care homes resisted the possibility of residents as carers, so that when someone was dying, the role of the resident was restricted by the actions of care staff. This level of reflection over time was illustrated by the example of Alice. I have described in Chapter 6, how in Regis Home when it was decided that Alice was 'dying' and her friends were not invited to participate in her bedside vigil, I recognised the significance of this omission and took action, so that her closest friends could visit her before she died and say good-bye to her. In reflecting on this several years later, I realised that, in part, the role of the 'living' residents was being *produced* through what I perceived to be a constraint. Rehabilitative 'living' did not include the role of carer to 'dying' residents. This suggested to me that power was also productive, even though what was produced might have seemed to be restrictive in the way that particular practices excluded the possibility of other kinds of death that could have been produced in these care homes.

#### **8.4.1      Analysing data – dissecting lives?**

The process of fieldwork, analysis and writing up has involved a range of feelings. One of the questions that underpinned my exploration in the thesis, and part of the rationale for the sequestration of death was why death and dying should be such a sensitive issue. This had implications for me as a researcher, too, and I recognised that doing this type of field work would evoke memories of people who had died, as well as producing new relationships during my fieldwork and the associated loss of these residents when they died. I believed that I needed to be aware of what I was bringing to the situation, and to be able to separate this out from the data, at least to some extent. Therefore, I arranged to have supervision sessions modelled on those used in counselling practice and similar to clinical supervision, and I met with a supervisor every six weeks and discussed the impact of the fieldwork on me and how I felt about what was happening. I also explored what I



brought to the situation and what it was that I might be trying to resolve for myself in the study.

Part of the ongoing dilemma, and that which arose in both my academic and (private) clinical supervision described above, was my tendency to take a psychodynamic approach to analysing my field work data. I found myself asking *why* and wondering about the individual psychodynamic motivations of those people in the study, as much as *what* people did and *how* events happened. This concerned me because I was taking a sociological approach to 'death and dying' in care homes for older people. I found it difficult to resolve this tension and experienced frustration throughout the fieldwork and the analysis. However, having analysed the data, the tension did not intrude into my writing up of this thesis. Indeed, by being able to talk about what I experienced as a dilemma, rather than suppress it, I argue that I was more able to focus on the sociological aspects of what was taking place. This is not to deny individual psychodynamic aspects that were also operating, but to recognise that I was taking one focus within a particular discipline. From this, I would argue that, while the aim of my thesis was to capture the social aspects of 'death and dying' in care homes for older people, there were many other interpretations that could have been made from different disciplinary aspects. Indeed this is consistent with my methodological approach of subtle realism.

This tendency to want to analyse the data in different ways, was not the only tension in the thesis. I also found the analysis extremely painful. By this I mean that I was concerned about the way that I felt I was 'dissecting' the residents in order to be able to code my data and possibly make some generalised observations. However, after the analysis, I recognised that I could 'bring back' the residents as whole people in the interpretive vignettes, which I have used as illustrations, and which, represented experiences and events that I commonly witnessed. Therefore, the process of writing up has been restorative to both those people who died whom I call 'ghosts' and to me.

The experience of my fieldwork, stayed with me long after the analysis was completed. It might seem to be self-evident that I was drawn to this type of work because I cared about the plight of older people in care homes. I have illustrated how each individual resident had to be able to cope with his or her experience of the disintegration into death. Individual researchers who work in a sensitive area are expected to be able to cope with 'death and dying' to the extent that he or she has to be able to make academic sense of what is taking place. I have discussed what I put in place to help me to cope and how, from a psychodynamic perspective, I was able to explore 'death and dying' while keeping it at a safe distance academically. What I mean by this is that, in some ways, my 'ordering' of this thesis kept my distress bounded as an academic explanation of what was taking place. In this way the thesis reflects the nature of the institutional life that I was recording, which also ordered and contained 'death and dying'.

However, this did not succeed entirely, because I was emotionally distressed by much of what I saw and frustrated by the way that pain and suffering could be dismissed as a 'normal' part of ageing and dying. I would argue that people who work in the research areas of society that are marginalised are more likely to be in need of support. I have discussed the value of sharing ideas and argued for clinical supervision for researchers working in this field. I will argue in the next section that this is also the case for the staff who work in these settings.

In order to be able to cope with my outstanding emotions, which I have called ghosts, I have suggested ways of making things 'better' for those residents who continue to be treated as docile bodies for whom the trajectory to death is prescribed by the dominant features of the institution of care homes. This is what I turn to next.

## **8.5 Implications for further research and practice**

During this thesis I recognised, and hopefully, reflected the messiness of frail and deteriorating, problematic bodies which were kept separate from the wider society and

which have been given over to the care of staff who managed with little resources and training. I hope that I have given an account of how they did the best that they could do under the circumstances, and how these circumstances also determined their professional responses to 'death and dying'. The experience of participant observation has made me much more sympathetic to their plight.

However, I argue that, without an in-depth understanding of what took place in these institutions, there is no way of changing the experience of dying for their residents. Furthermore, taking a more in-depth response requires a change in the culture of care homes away from the symbolic practices of care that has produced a new form of rehabilitative 'living', and, subsequently, a new form of 'death and dying'. This thesis has shown that the focus on residents' bodies and symbolic practices, not as part of responding to their diverse needs, but as part of a production of ageing bodies into categories, failed to meet the needs of residents on all levels. This has implications for the personal and professional development of carers. Home managers and inspectors would need to recognise the impossibility and futility of categorising residents into 'states' that bear no relationship to the residents' needs and which only fulfil an institutional purpose. Furthermore, rather than countering the dangers of institutionalisation, 'living' as rehabilitation has produced an institutional form of 'living' that does not bear a direct relationship to the day-to-day experience of residents and their carers. My data also showed how the emotional needs of care staff in homes for older people were not included as legitimate aspects of their caring role. In the delivery of a new type of care, care staff would need to recognise that residents are best placed to dictate their own needs, both as people near to the end of their life, with complex needs, and as people with the capacity to contribute to caring. Many of the residents had been carers most of their lives and also many had survived multiple losses. My data showed that the caring role of residents through close friendships and their awareness of coping with loss had been largely ignored. Part of this recognition would also need to come from the paid

carers through an awareness of themselves as people with diverse emotional needs and abilities, rather than *producers* of emotional norms.

I argue that such a new culture would need to support a direct engagement with the needs of carers and 'dying' residents and that such a cultural shift would have the potential to support the provision of more meaningful forms of care. I would also argue that part of a new culture would be one that would recognise and acknowledge residents as people first. However, this is not straightforward. Delivering an appropriate level of care that takes a person-centred approach, as is the rhetoric of good quality care (Hockley and Clark, 2002), requires recognition of how that person is produced. Throughout the thesis I located the self as one that has implicitly resided in the body as a taken-for-granted self. Hallam *et al.* (1999) challenge this notion of the body as a container of an individual self, which ceases to exist after death. Lawton (2000) has argued that even in hospice settings that specialise in good quality care at the end of life, the problematic, disintegrating dying body stands in for individual identity, causing the dying person to withdraw into a marginalised state of isolation and for hospice staff to collude in this sequestration of 'dirty dying'. Without a recognition of the self as other than something that resides in a body, and an approach that does not define residents according to their bodily states, the practice of care for residents in care homes cannot easily change.

Finally, therefore, without such an in-depth understanding that such ethnographic studies can bring, the rhetoric and practice will remain divided. Forms of care may change, but for practitioners and policy makers to be able to bridge this gap requires more than protocols and resources, although they clearly play a vital role, they require a new culture underpinned by the findings of this type of research that supports a direct engagement with the needs of carers and dying residents and which recognises residents as people first.

## APPENDIX 1

### The recommendations made to the Department of Health based on the findings of the commissioned project

We would recommend that inspection and regulation should expect homes to provide care in line with the Trent Palliative Care Core Standards adapted as follows:

**Standard 1 *Collaboration with other agencies.*** That there is evidence of effective collaboration with other agencies, professional and voluntary providing continuity of care and support to dying residents and their carers.

**Standard 2 *Symptom control.*** All dying residents have their symptoms controlled to a degree that is acceptable to them, and achievable by multidisciplinary team intervention within current palliative care knowledge.

**Standard 3 *Resident/carer information.*** That dying residents and their carers have the information they seek, relating to the diagnosis and progress of the disease, care options and allied support services available to enable them to make informed choices.

**Standard 4 *Emotional support.*** That dying residents and their formal and informal carers have adequate emotional support.

**Standard 5 *Bereavement care and support.*** That formal and informal carers of the dying person and other residents have access to bereavement support.

**Standard 6 *Specialist education for staff.*** That specialist education and training is gained through courses, work experience and seminars and is kept up-to-date.

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